

Constructing Life Narratives: How Novels and Policy Discourses Represent and  
Respond to Life Stories About People with Mental Disabilities

by  
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## **Abstract**

This dissertation explores how an interdisciplinary analysis may contribute insight into how literary and policy discourses construct the life experiences of people who have mental disabilities that impair their ability to communicate their own life stories. Chapter One explains why a more comprehensive understanding of the cultural construction of mental disability may be achieved by exploring interdisciplinary relationships between social work, disability studies and literary theory. Subsequent chapters examine theoretical assumptions and frameworks associated with these contributing disciplines in greater detail, across systematic and interpretive analytic approaches. In addition, key concepts and questions relevant to constructing a vocabulary that facilitates collaboration between the contributing disciplines are considered. This literature review informs a methodology for undertaking an interpretive discourse analysis of pertinent policy and novels that depict disability within the context of Ontario's 'Institutional Cycle'. Specifically, the research attempts to answer the following questions: What is the relationship between the representation of mental disability in literary narratives and public policy discourses about mental disability; and, how may an interdisciplinary analysis of literary and policy discourses inform policy planning and the provision of services for people with mental disabilities in Ontario? Chapters 6-8 analyze the literary and policy data across Establishment, Reform and Dismantlement phases of the Institutional Cycle to arrive at a set of findings and recommendations that explain relationships between policy and novels across the phases of the Cycle. Finally, key themes for consideration in policy planning for people with mental disabilities are identified as priorities for action in an emerging 'post-institutional' era, in Ontario.

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## **CHAPTER 1- Interdisciplinary Inquiry**

### **Introduction**

Disability is a social construction (Dunn 413; Michalko 174; Prince 6; Scull 8); a concept that is represented, challenged and revised across different cultural texts, including literature and policy (Mitchell & Snyder 205). According to Tanya Titchkosky, “disability, made by culture, is a prime location to reread and rewrite culture’s makings” (12). Mental disability, specifically, poses definitional challenges because the nature of associated impairments is not always immediately identifiable, and may be interpreted from a range of theoretical perspectives. For this reason the representation of mental disability lends itself to interdisciplinary investigation. Different perspectives and representations of mental disability have particular implications for people whose ability to speak for themselves is impaired. The manifestations of severe disability also pose challenges for social workers who are mandated to work for the best interests of their client as their “primary professional obligation” (Ontario College of Social Workers and Social Services Workers, 1). The responsibility attached to their role is magnified when social workers are called upon to speak *for* their clients instead of working collaboratively *with* them to advocate for appropriate services and supports so that they may assume their rights and responsibilities as social citizens (Drover, 2000, 37). In carrying out this role, social workers in all fields of practice, including direct intervention with individuals, service administration, social planning, policy development and analysis, need to look outside their own professional theories if they wish to challenge dominant cultural assumptions that have marginalized clients’ expertise in relation to their own life

experiences (Bagatell 414; Beresford & Croft 299; Cambridge & Parkes 713; Cushing 160; Peat 657-658). By reading widely from both literary and policy texts, and thinking in an interdisciplinary way about the social and cultural space between these discourses, social work researchers and practitioners may contribute to a richer representation of the life experiences of people with mental disabilities. An interpretive discourse analysis of the ways that literature and policy intersect to construct mental disability may, in turn, help social workers better provide personal supports, advocacy, program or policy development for people who cannot speak for themselves, or who are not recognized as reliable self-advocates.

### **Interdisciplinarity between Social Work and Literary Studies**

The study of literature seems to readily accommodate an interdisciplinary approach because humanities disciplines tend to be less tightly bound to prescriptive theory (Goldstein 41; Iyer 127; Riessman & Quinney 407; Whalley 242-243). Julie Thompson Klein explains that “literature assumed early prominence in the history of humanities, it was a primary site for importing new developments, and it has been a major locus of interdisciplinary theorizing” (2005, 83). Because many kinds of knowledge can be communicated as story, literary narrative can adapt itself to many kinds of inquiry, including social work.

On the other hand, the interdisciplinary potential in social work lies, at least in part, in its history as a kind of hybrid discipline that has tried to be both science and art (Howe 518). Social work has been drawn to a scientific justification for its interventions for the same reasons that the social sciences, generally, have tried to gain legitimacy through adopting scientific models. Glenn Drover (1998, 84) argues that, from the outset



in Canada, social work emphasized the importance of scientific diagnosis in order to legitimize the profession as something more substantial than a moralizing charitable organization society. As Howard Goldstein observes, “within a society that was enthralled with the aura and the remarkable benefits of the new sciences and technologies, certain leaders... departed from the profession’s humanistic roots and elected to define social casework as a science” (33). Over time, this scientific approach to managing human need has not co-existed easily with social work’s other founding humanistic influences.

Social workers who tried to defend social work’s humanistic roots have, until relatively recently, not been taken very seriously. Still, some persevered in arguing against so-called rational methods that attempted to reduce social work interventions in terms of quantifiable outputs. Lydia Rapoport notes that

[s]ocial work, like art, is engaged in problem solving, be it the problem of expression, communication, transformation, or change. Both deal with human materials or human themes and both require an intimate ‘knowing and contact’. Both call for creative and imaginative use of self. Both require a special kind of distance and objectivity. (151)

This humanist approach to professional social work practice articulates the relationship between worker and client as something that cannot be explained by rational theory. Many social workers who recognize the dynamic and interpretive aspects of their relationships with individuals and client constituencies employ metaphors of art and drama in order to fill knowledge gaps that science cannot address (Martinez-Brawley & Zorita 205).

Story is also utilized as method by some social work practitioners and theorists, including Applegate, who believes that “[e]ach case history is a story and, from a posture of respectful curiosity, [social workers] try to help the client tell that story in her own voice” (151). Goldstein brings together the ideas of drama and story in observing that “[c]lients recount a story—a narrative of how they believe things came to be, how they ought to be, perhaps how things might yet be. Entering into the context of the client’s life is not far removed from witnessing (and respectfully becoming part of) a drama replete with plot, protagonists, antagonists, crises, and critical choices” (30). The concept of social workers inviting clients to tell their life stories has contributed to a number of therapeutic interventions that adapt the language of literature to meet therapeutic ends. These include some narrative approaches, bibliotherapy and cognitive behavioural approaches where clients are taught skills to “re-story” problematic personal plotlines (Applegate 150).

This interest in story and the language of literary theory is not confined to social work practice with individuals. Along with the art and science tension, social work is a profession that concerns itself with both individual and larger institutional change. Structural social workers “embrace both the judicial and the therapeutic in single acts of intervention—they judge *and* they treat; they control *and* they cure. In this way private and personal experiences are politicized” (Howe 517; emphasis in original). In professional practice, social workers are educated to recognize a relationship between personal stories and larger cultural narratives: “The interpretation of personal experience is always embedded in the larger stories, myths and normative structures that permeate Canadian society” (Neysmith, Bezanon & O’Connell 19). Social policy responds to these larger stories and contributes to those normative structures in the form of legislative,

policy, and planning texts. Reissman and Quinney point out that, “[a]s individuals construct stories of experience, so too do nations, governments, and organizations construct preferred narratives about themselves” (393). Success in social policy planning may be determined by how well policy makers interpret individual stories that are woven together into cultural narratives, as a culture’s legal and narrative discourses mutually inform each other (Couser 2007, 81-83).

Narratives are legitimized to the extent that they succeed at representing cultural attitudes, values and storylines with which the reader can identify (Cohen 51; Holland 212; Lyle & Gehart para. 18-23). Therefore, literature “by its very nature is the opposite of an escape: imagination is a realising-process, making the world real, making us real” (Whalley 199). If literature may be read as interpretations of the world we live in, for some theorists it follows that literary narrative is inevitably political:

What is literature? It is a discourse which exploits in periods of economic and institutional disengagement the fictiveness of utterance by announcing that fictiveness, and thus has the capacity to maintain the redundancies of its culture, to modify those redundancies, and to undermine them. Thus it has the capacity to support the economic interactional patterns of its culture, to modify them, and to destroy them. (Peckham 228)

An explicit relationship between literature and policy can be traced back to the origins of political satire. Eighteenth century literature is particularly renowned for its satirists, and Klein reflects upon this period to consider how satire may be seen in terms of an interdisciplinary relationship between literature and matters of social welfare and political economy where

Jonathan Swift connected madness and the theory of sublimation to the

realms of empire, philosophy, religion, poetic convention, female beauty, and human pride. Alexander Pope explored a theory of ideology that situated poetry in its socioeconomic context as a coordination of aesthetic value and exchange. The force of Pope's insight into the commodity status of poetry depended on the premise that economy and poetry were divergent spheres. (2005, 20)

While satire explicitly undermines social conventions, political ideologies and cultural values by exaggerating and undermining them with humour, literature's political import is by no means confined to satirical narrative genres. Martha C. Nussbaum focuses on the novel, specifically, as an accessible, current narrative genre that has much to contribute to the process of policy making, generally. She believes that,

the novel constructs a paradigm of a style of ethical reasoning that is context-specific without being relativistic, in which we get potentially universalizable concrete prescriptions by bringing a general idea of human flourishing to bear on a concrete situation, which we are invited to enter through the imagination. This is a valuable form of public reasoning, both within a single culture and across cultures. For the most part, the genre fosters it to a greater degree than classical tragic dramas, short stories, or lyric poems. (8)

The historical context for the rise of the novel as a literary genre, and changes in the social construction of mental disability are, in fact, related.

Patrick McDonagh looks primarily at novels to inform his historical analysis of the construction of mental disability in Western culture. He finds that "social concerns can be reproduced in literary works, making literary documents important sources of information regarding the symbolic or ideological function of people with learning

disabilities at the time of the composition of the text” (2000, 49). McDonagh’s literary analysis culminates in the finding that the symbolic representation of mental disability in literary texts continues to both validate and challenge dominant social discourses about mental disability and gender which, in turn, shape policy positions that can exercise influence over real people’s personal narratives.

According to Lennard Davis (1997), the political and scientific advances associated with industrialism contributed to the evolution of the novel in the nineteenth century, and also influenced the representation of disability:

I am not saying simply that novels embody the prejudices of society toward people with disabilities. That is clearly a truism. Rather, I am asserting that the very structures on which the novel rests tend to be normative, ideologically emphasizing the universal quality of the central character whose normativity encourages us to identify with him or her. Furthermore, the novel’s goal is to reproduce, on some level, the semiologically normative signs surrounding the reader, that paradoxically help the reader to read those signs in the world as well as the text. Thus the middleness of life, the middleness of the material world, the middleness of the normal body, the middleness of the sexually gendered, ethnically middle world is created in symbolic form and then reproduced symbolically. This normativity in narrative will by definition create the abnormal, the Other, the disabled, the native, the colonized subject and so on. (22)

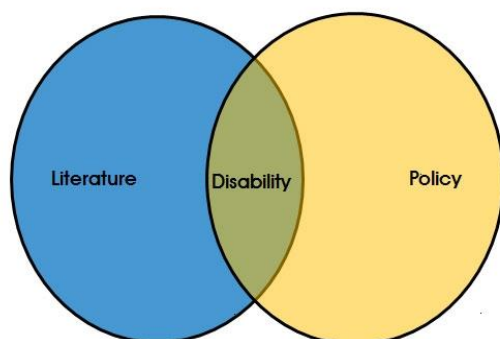
Social work evolved at the same time as the novel, as a result of the same influences, to realize similar objectives. Darwin’s theory of evolution, the development of statistics as a scientific tool and Quetelet’s calculation of the “normal man” all contributed to a politics

of eugenics (Davis 1997, 11) that is evident in early Canadian social policy designed to segregate those designated as “feeble minded” from mainstream (normal) society (Simmons 1982, 53-58). Those assumptions inherent in policy decisions regarding people with mental disabilities were reinforced by traditional literary stereotypes attached to disability-- the monster, the villain, the fool, the martyr (Margolis & Shapiro 18-21; McDonagh 2000, 50-53; Mitchell & Snyder 208-209). If it is true that “all fairytales tell us something about reality” (Scholes 247), then policy attempts to establish the terms and conditions for how we live in the real world.

Given the political underpinnings that determine social work practice, as well as literature, it is possible that a more comprehensive understanding of the social construction of mental disability may be realized by studying relevant literary and policy discourses together (Fig. 1), provided a method can be found to facilitate communication between disciplinary languages. Emery Roe suggests that a relationship between literary and policy theory may be forged through construction of a metanarrative that manages to meet the epistemological requirements of all contributing perspectives. This, however, can be problematic in interdisciplinary research where, typically, “literary theorists don’t know much about policy, and practicing policy analysts certainly don’t know much, if anything, about literary theory” (Roe xiii). At the same time, there are differences in how language is used in different disciplines (Yanow 2000, 64).

Roe’s theory of narrative policy analysis begins with the observation that language is not neutral, nor is it particularly easy to translate key concepts such as text, narrative, discourse, or story between disciplines. George Whalley elaborates on the

**Figure 1- Interdisciplinary Construction of Disability**



challenges of using the same language to communicate poetic and political purposes, noting that

‘[o]fficial’ and political writing, earnest and impersonal in tone and of modest literary accomplishment, may seem to be assailable only in its ‘ideas’ and logical connections. Yet, couched in language, it must be criticized and analysed in terms of the way we know language functions, confident that we can see why it was written in that way and no other way. (86)

The interdisciplinary researcher must have enough expertise in all contributing disciplines to at least be familiar with their respective ‘languages’ in order to achieve a satisfactory breadth of understanding to communicate between them.

Patsy Healey demonstrates how the ability to communicate between different types of texts is a fundamental aspect of policy planning:

Planning is an interactive and interpretive process... Planning processes should be enriched by discussion of moral dilemmas and aesthetic experience using a range of presentational forms, from telling stories to aesthetic illustrations of experiences. Statistical analysis coexists in such processes with poems and moral fables... Planning involves invention. (242)

Introducing terms like invention in relation to policy planning speaks to the creative aspects of interpretation in relation to the construction and evaluation of policy texts. In the construction of texts, be they policy or literary, an imposed structure can only take the author so far, and writers are always ‘going outside the lines.’ For example, any theory that attempts to define ‘what is literature’ is simply an invitation to challenge and reinvigorate prevailing critical assumptions (Davenport 44-46).

Healey’s endorsement of diverse sources to inform policy planning opens the door to a wider range of stakeholder perspectives. Social welfare advocates argue that the consumers of social services have a relevant expertise to contribute to social planning and policy development (Beresford & Croft 302; Couser, 2007, 73; Friedman 114; Healey 236-237; Hudson 389). Unfortunately, social work has had a rather poor track record in recognizing, much less incorporating, the expertise of service users in general (Beresford & Croft 300; Gambrill 169; Hawkins, Fook & Ryan 10). Even when social workers are inclined to work in ways that respect and incorporate client knowledge, the inevitably subjective elements associated with any interpretation make it difficult, if not impossible, to generate a social work theory that is capable of providing a reliable model of practice for representing the life experiences of people with severe mental disabilities.

In working with people who have significant intellectual or mental health impairments, it is far too easy for social workers to make false assumptions, or produce what Claudia Malacrida refers to as “sanitized memories”(403): historical accounts or client memoirs that minimize or overlook evidence of oppression and abuse. Therefore, it is incumbent upon the social worker to try and find direction from other narratives in order to “develop skills in translation, in constructive critique, and in collective invention



and respectful action to be able to realize the potential of planning” (Healey 248).

Training in literary theory may facilitate the development of these kinds of skills.

The variety of theoretical perspectives informing the substantial professional practice of social work makes it difficult to define its disciplinary boundaries. As Adrienne Chambon observes, “the accepted terminology of social work is always at a difficult crossroads as it accommodates a diversity of logics and languages into a single professional field” (67). Just within the branch of social work that specializes in planning, Rothman and Zald identify several disciplinary influences, including “sociology, political science, anthropology, economics, organizational theory, as well as psychology and social psychology” (145), which they see as contributing to an absence of “a specific theoretical knowledge base” in planning. Therefore, the interdisciplinarian’s preoccupation with communicating between disciplines should not overlook important debates that regularly occur *within* disciplines about what constitutes appropriate method or theory.

Even though there is no consensus about a comprehensive theory of literature or a theory of social work, each set of disciplinary discourses serves a normative function. Furthermore, literature and social policy both influence the emerging discipline of disability studies: “one bridge connecting conventional policy analysis and contemporary literary theory is the importance both place on the role of stories and storytelling in securing and endorsing the assumptions needed to make [planning] decisions under conditions of uncertainty and complexity”(Roe 9). Social work’s affinities with the humanities, and literary studies specifically, are not as widely recognized as its relationships with disciplines in the social sciences, and even natural sciences. Exploring social work theory and literary theory together, in an interdisciplinary fashion, may result

in an enhanced critical analysis of narrative and story in both disciplines, inform an approach to disability studies, and also a process for accessing life narratives that belong to people who have limited or no ability to speak for themselves.

## **CHAPTER 2- Literary Theory**

### **What is Literature?**

Given that this interdisciplinary study aspires to look at theories of literature together with disability, social policy and planning, it is useful to try and organize a literature review within a framework that can accommodate a spectrum of perspectives across the contributing disciplines. Jerome Bruner (1993) differentiates between explanatory and interpretive theoretical paradigms because he believes that while interpretation may fall outside the realm of systematic accountability, he also knows that “what is not subject to the constraints of conventional computability is not ‘outside’ the grasp of the human sciences” (126). In that spirit, questions of literary, disability and policy theory will be considered from different perspectives, ranging from those that attempt to establish a systematic approach to theory, to those that lay more emphasis on how interpretation of different types of discourse informs analysis and determines what constitutes knowledge.

Ever since Aristotle described the elements of tragedy in the *Poetics*, philosophers have attempted to organize literary discourse into distinct categories or genres. Similarly, literary critics are also identified as belonging to different theoretical traditions, and consensus between critical perspectives fails to occur, perhaps because a

theory of literature is logically impossible, for there are no necessary and sufficient conditions for counting a piece of discourse as a work of literature.

The concept is ‘perennially debatable’: every proposed condition ‘is always open to fundamental question, challenge, rejection, and replacement’... No set

of properties is shared by all pieces of discourse counted as works of literature; there is only a set of ‘family-resemblance’ properties, some present in every work of literature, but none in all. Further, the concept is ‘perennially flexible’: new conditions are always possible to accommodate works possessing not only some of these family-resemblance properties but other properties as well... At best a theory of literature can only be a recommendation to give the greatest weight to certain conditions or properties. (Brown & Steinmann 42)

Paul Hernadi agrees that many critics doubt the feasibility of defining literature at all (1981, 100), and these positions do not even take into account the evolution of electronic mediums that can make anyone with access to the internet an author with access to a potential audience of millions. This contemporary reality only further reinforces Davenport’s position that the concept of literature is now just too broad, and incorporates too many genres and experiences to accommodate any coherent theory:

Theory cannot be comprehensive, since the morrow may always bring a new work of literature which does not fit the theory. Second, the attempt at comprehensive theory, given that it is impossible, is not only fruitless but destructive of literature itself, since theories will tend to serve as public prohibitions against certain kinds of experiments. (41)

Attempting to articulate a theory of literature, even one that focuses exclusively on all the different ways narrative literature is constructed must produce a model so broad that it cannot really communicate anything meaningful. As a result, “[w]e know what literature is only vaguely, so that any attempt to remove that vagueness in a definition actually falsifies our knowledge of the word, rather than clarifies it. To define is to mark off

boundaries distinguishing what is literature from what is not, but our knowledge of literature has no such defining boundaries” (Hirsch 26). Still, even after taking into account the enormous breadth and depth of the literary canon, the researcher must take a stand, somewhere, before any meaningful analysis can proceed.

### **Mimetic and Structural Literary Theory**

As this research proposes to undertake an analysis of how mental disability is constructed in narrative and policy discourses, it makes sense to explore literary theory that focuses on narrative as both a representation of human experience and as a language construct. This starting point correlates well with Paul Hernadi’s premise that literary criticism is primarily preoccupied with structural and mimetic aspects of the text:

Some critics see literary works merely as instruments of mimesis: words representing worlds. Others see them mainly as instruments of communication: messages from authors to readers. Because all instances of spoken and written discourse potentially represent and communicate at the same time, it seems unwise, if not self-deceiving, to restrict one’s concern to what the work is or how the work functions. (1981,107)

While many people think of reading as a private and personal experience (Ohmann 91), an examination of both the mimetic (interpretive) and communicative (structural) functions of literature elucidates the social function of literary narrative in terms of its capacity to influence the construction of cultural concepts and categories, including disability.

In the *Poetics*, Aristotle takes considerable pains to articulate the mimetic quality of the different poetic arts. Aristotle sees the process of imitation as one that is natural to

mankind, as “all men find pleasure in imitations” (44). For him, “the capacity to produce an imitation is the essential characteristic of the poet” (43). Thus, it would seem that a great capacity for imitation must go hand in hand with extraordinary insight into the world being portrayed in a narrative work.

As David Lodge observes, “[i]t is a commonplace that the systematic study of narrative was founded by Aristotle, and scarcely an exaggeration to say that little of significance was added to those foundations until the twentieth century” (24). Therefore, it is hardly surprising that many theorists continue to identify Aristotle’s concept of mimesis as a defining feature of a literary text:

“Mimesis” as used, for example, by Aristotle... still carries some of the force of its origin in dance or mime. Mimesis is an inward act of reproduction whereby the thing imitated is internalized by the imitator and so learned. In mimesis the thing imitated is then turned into an action and thereby externalized, brought out into the open for the imitator or for those who watch the imitation. In mimesis the imitated becomes exposed to knowledge. (Miller 158)

Aristotle’s rationale further prescribed how different genres are most appropriate for reproducing different kinds of human behaviour. He assigned the dramatic genres of comedy and tragedy so that “the former takes as its goal the representation of men as worse, the latter as better, than the norm”(Aristotle 43). There is little room for ambiguity in designating the type of story and its appropriate genre.

Contemporary allusions to mimesis may emphasize how words represent worlds by portraying a fictional experience in a realistic and convincing manner. For example, Altieri’s definition of mimesis takes both language and the narrative world that

contextualizes it into account: “[l]iterature can be called mimetic—not because it copies experience but because it directs us to recreate imaginatively a world in which the speech acts presented would be significant” (68). Raymond Mar and Keith Oatley begin their analysis of the function of fiction from a mimetic theoretical orientation, arguing that “stories model and abstract the human social world. Like other simulations (e.g., computer models), fictional stories are informative in that they allow for prediction and explanation while revealing the underlying processes of what is being modeled (in this case, social relations)” (173). They attempt to construct a rationale for linking the imaginative content of stories with a predictable system of analysis for articulating the function of fictional narrative in people’s lives. Their position is that human beings possess a kind of “schema” (177) for stories that is hardwired into us.

Likewise, Jerome Bruner (1993) finds that “we have access to some sort of mental narrative generator very early on, one primed to incorporate the forms of story on offer in the culture, but which nonetheless may be characterized by some universal architecture” (134). This architecture is vital, but it is not the entire explanation for our comprehension and appreciation of narrative:

Struggles with order-preserving transformations, with deletion rules and caselike grammars, may help us toward a formal grammar and something approximating computability. But... I doubt this will take us all the way. For I doubt whether the hermeneutic process, given the complexities already mentioned, is reducible to computable steps. More likely, it is upon the development of an interpretive anthropology and counterpart cultural psychology that we shall have to depend for elucidation. (Bruner 1993, 135)

Mar and Oatley's 'architecture' make it possible to take complex social relations and, through a process of selecting what details to incorporate, contain them in a story that "can be seen to generalize from one instance to many similar instances" (177). Decisions around what information to incorporate and how to present it, however, are a matter of authorial selection in order to tell a certain type of story, as Aristotle indicated in his explanation of different poetic genres. An authorial representation of an idea or experience is, in turn, subject to subsequent interpretations by readers that are based on their own experiential resources. From this perspective, all stories can be understood as a triangle of binds between author and reader, reader and protagonist, protagonist and author (Manguel, 67).

Mar and Oatley's argument leads them to propose that "[t]he debate on what constitutes a useful categorical definition of a narrative may be a conceptual dead end. Perhaps it is not how a text is structured that really defines narrative, but its content and our responses to this content. A prototypical-content approach, rather than a categorical-structure approach could thus provide greater utility" (174). In other words, the structure of a literary work is useful for categorizing it, but it soon becomes apparent that literature cannot be fully comprehended by explaining its components: the literary work is more than the sum of its parts.

This view invites a critical impatience with Aristotle on the part of some contemporary theorists, including Edward Davenport, who finds that Aristotle's theory of the poetic arts is, ultimately, irrelevant to determining contemporary definitions of literature:

Aristotle... was ignorant of the literature of the past two millennia. It is even said that Aristotle was not trying to give an answer to the question 'What is



literature?', but was only giving a description of the particular drama of his own time; according to this argument Aristotle had nothing to say about what makes literature great or second rate, but only explained how to tell when a play diverged from the norms of his time. (40)

Aristotle's pervasive influence on literary theory endures, however, because his dramatic method has been abstracted to the much wider range of genres familiar to contemporary readers, and it has informed what Lodge identifies as an evolving "poetics of fiction"(24). Thus, Mar and Oatley have no qualms about linking Aristotle's theory of tragedy to the more general category of story.

As different kinds of action are the focus of different classical literary genres, so language is utilized in deliberate ways to facilitate the representation of different types of action. These distinctions of language assigned to identified literary genres have invited a systematic analysis of language and its components. Roland Barthes (1989) believes that a "genuine" theory of language that we understand as rhetoric came to literature

from antiquity, [and] reigned in the Western world from Gorgias to the Renaissance—for nearly two thousand years. Threatened as early as the sixteenth century by the advent of modern rationalism, rhetoric was completely ruined when rationalism was transformed into positivism at the end of the nineteenth century. At that point there was no longer any common ground of thought between literature and language. (42)

Barthes draws upon the work of Ferdinand de Saussure, among others, to articulate a renaissance in language in what he sees as a "new union of literature and linguistics" (43) that he refers to as semio-criticism. This approach is grounded in an understanding of writing as a system of signs: a perspective that "does not imply a lack of interest in

language but, on the contrary, a continual return to the ‘truths’—provisional though they may be—of linguistic anthropology” (43). The ‘truths’ that Barthes depends upon in language were articulated by Saussure in a theory of semiotics to explain how words communicate meaning in language.

Saussure understands language as comprised of signs: “unions of meanings and sound-images” (1985, 34) that are inextricably linked, like two sides of a coin. There is a relationship between a concept (signified) and a word-image (signifier) that combine to construct a sign that is both arbitrary, yet incontrovertible: “the signifier chosen by language could be replaced by no other” (1985, 40). According to Bruner, this aspect of language liberates narrators from “the more binding restrictions of pure mimesis” (2002, 96), as signs do not have to resemble their referents.

Furthermore, Saussure’s distinction between *langue* and *parole* in language concretizes a system of understanding that inheritors of language need to be able to internalize in order to communicate narrative, even if it is not done consciously. “Langue is the system of language, the system of forms (the rules, codes, conventions) and parole refers to the actual speech acts made possible by the langue. Utterances (paroles) are many and varied and no linguist could hope to grasp them all. What linguists could do was to study what made them all possible” (Rice & Waugh 7). Knowing how a system of language operates may enrich a critical understanding of the choices made by authors in the construction of different types of narratives.

As a leading thinker in a structural approach to language, Saussure’s theory of language may be considered as a major contribution to a system of narratology. Oliver Sacks adapts this concept in an interesting way, identifying it as a necessary approach to understanding his patients who had severe mental disabilities. He says that in trying to

test the functioning ability of patients “we were far too concerned with ‘defectology’, and far too little concerned with ‘narratology’, the neglected and needed science of the concrete” (1998, 183). Indeed, narratology does concern itself with the concrete structures of language, upon which all interpretation must ultimately hang. David Lodge further elucidates the aims of narratology by pointing out that

[i]t is often said that this kind of approach is more rewarding when applied to narratives of a traditional, formulaic and orally transmitted type rather than sophisticated literary narratives; and the exponents of narratology themselves frequently remind us that their aim is not the explication of texts but the uncovering of the system that allows narrative texts to be generated and competent readers to make sense of them. (26)

This entails drawing the literary critic’s attention to factors that are vital to reading narrative. Because many readers just internalize the narrative conventions appropriate to their own culture, “we stumble when we try to explain, to ourselves or to some dubious other, what makes something a story rather than, say, an argument or a recipe” (Bruner 2002, 3-4). Just as native speakers of a given language generally understand its rules of grammar without necessarily being able to explain them, so too do we tend to understand narrative conventions without necessarily being able to articulate them.

Peckham agrees with Saussure when he argues that “[a]ny individual is a precipitate of the indescribably complex control system which is language; with infinitely rare exceptions, his presence or absence, his existence or nonexistence, makes no difference” (226). However, Peckham then proceeds to point to a possible explanation for the lack of consistency within language when it comes to defining abstract concepts. He suggests that although behaviour is controlled by one’s language system, “the brain’s

capacity for random response, deviance (innovation, creativity, the imagination) is constantly being introduced in, on the whole, minute and statistically insignificant amounts” (226). Small differences of interpretation between individuals are magnified within academia where communities of thinkers who share knowledge of specific disciplines use language in distinct ways that may not be consistent across different disciplinary cultures. This creates challenges for interdisciplinary researchers trying to generate a vocabulary to effectively communicate knowledge across contributing disciplines.

As a result, some interdisciplinarians may be tempted to accept Robert Scholes’ position, which argues that Saussure’s assertion of an “unbridgeable gap between words and things, signs and referents” (238) has been dismissed by French structuralists and their followers for being “too materialistic and simple-minded. Signs do not refer to things; they signify concepts, and concepts are aspects of thought, not of reality” (238). In Scholes’ view, “if language were really a closed system, it would be subject, like any other closed system, to entropy. In fact, it is new input into language from non-verbal experience that keeps it from decaying” (238). Saussure distinguishes between concepts and the signs used to identify them, but he fails to acknowledge how language is actually a porous system, and the product of an extra-linguistic reality, which is not static. Language does change over time, along with changes in cultural values. In an age of electronic communication media that connects diverse cultures in ‘real time’, the stability of any language system is, arguably, even less predictable than it has ever been. Therefore, a semiotics of literature cannot completely account for how narrative is communicated and understood.

Saussure (1989) does acknowledge that while meanings of concepts are consistent across a language, their value is determined in terms of their relationship to other concepts: “If I state simply that a word signifies something when I have in mind the associating of a sound-image with a concept, I am making a statement that may suggest what actually happens, but by no means am I expressing the linguistic fact in its essence and fullness” (13). Michael Holquist’s theory of language may assist in further clarifying this distinction between meaning and value where he refers to Karcevskij’s semiotic model:

“In a ‘complete’ sign... there are two opposed centers of semiotic functions, one for formal values, the other for semantic values. The formal values of a word (gender, number, case, aspect, tense), represent aspects of signification known to every speaking subject which are more or less safe from any subjective interpretation on the part of interlocutors; they are assumed to remain identical to themselves in all situations. The semantic part of a word, in contrast, is a residue resistant to any attempt to decompose it into elements as ‘objective’ as formal values”’. (205)

From this perspective, signs have both enduring, objective qualities, but also possess a “residue” that defies categorization. This residue may further account for the dynamic aspect of language over time, as well as the lack of consensus around the meaning of abstract concepts, such as disability.

Sacks also refers to the residue of lived experience that is lost when physicians and other researchers attempt to write about disease or disability in an “‘objective’, styleless style” (1990, 230). In reviewing such texts, he laments that “nowhere, *nowhere*, does one find any colour, reality, or warmth; nowhere any residue of the living

experience” (230 emphasis in original). This observation draws attention to how language may just as effectively be employed as a means of control and oppression as it can to facilitate enlightenment, which is why Peckham believes that “[i]t is a sentimentality to conceive of language as ‘communication’. Rather language organizes, directs, controls, and modifies behavior” (225). This insight does not contradict a structural theory of language, but it does demonstrate that communication and shared knowledge is not the inevitable outcome when language is employed in sophisticated ways.

Other theorists elaborate further upon the autonomy or authority of the narrator to undermine the conventions of language, at least to some extent, in order to communicate his or her story in an original way. The unpredictability of human experience, along with the innovative ways that language may be utilized to interpret and communicate that experience as narrative or story, leads Bruner to believe that “[e]fforts to write generative narrative grammars have not been notably successful, for stories are too dependent upon the context of the telling, too susceptible to what seems like unprincipled recursion, too lacking in either a standard lexicon or in definable story parts” (1993, 135). There is enough flexibility or discretion within our language system that words may often be interpreted in multiple ways, in different contexts without making them unintelligible to others who share the same language. As a result, Whalley emphasizes the intention of the author as a determining factor of meaning in how language is used to construct a narrative:

Here we come upon the peculiar nature of language—the fact that we discover our meaning in the wording of it; for it is persons, not words, that mean. In matters of spelling, in identifying parts of speech, and even in classifying

figures of speech, we may be able to speak of “right” and “wrong” (i.e. correct and incorrect), but as soon as we are dealing with syntax and style we are dealing with the judgement of what “works”, what is “exactly right”, in an actual context... “rules” are indications, navigational instruments, not immutable imperatives. Here the only test is whether in fact a certain wording “works”, whether it is the best words in the best order—and perhaps nobody can say that for sure except the writer. (141)

For Whalley, judgments about how to organize language are inevitably subjective and not predictable in accordance with a systematic theory of language. However, a perspective that emancipates the narrator from the confines of a language system can be taken only so far, as there are obviously limits to how much an author or narrator can flout the rules of language and still be comprehensible.

Lodge identifies the emergence of the realistic novel as the historical point where structural theory ceases to adequately account for narrative, claiming that

[t]he rise of the novel as a distinctive and eventually dominant literary form finally exposed the poverty of neoclassical narrative theory, without for a long time generating anything much more satisfactory. The realistic novel set peculiar problems for any formalist criticism because it worked by disguising or denying its own conventionality. It therefore invited—and received—criticism that was interpretive and evaluative rather than analytical. (24)

While Lodge recognizes the contribution that narratology can make to the enriched comprehension of narrative texts, he also admits that “the structural coherence of narratives is inseparable from their meaning, and reading them is inseparable from

forming hypotheses about their overall meaning”(27). Thus, the mechanics of language and narrative structures are perceived to be inevitably enmeshed in interpretation.

The novel also introduced a democratization of literature, making it accessible to an increasingly literate population, representing a wider range of experience. Lennard Davis emphasizes how “the novel was historically an early modern form dependent upon early modern technologies... participating, both collusively and transgressively, in the transformation of social, political, and cultural life” (1998, 318). If this is true, then literature not only creates worlds, but also has the capacity to change the way we see our real world existence. Therefore, Richard Ohmann believes that

[t]he definition of Literature, capital *L*, is a social process. In it, as in all social processes, some groups participate more actively than others; some do not participate at all. The exercise of power is involved in the process; therefore, so is conflict. We don’t generally notice the power and the conflict except when some previously weak or silent group seeks a share of the power... The social definition of literature is always, among other things, a contest for cultural dominance. (90)

Returning specifically to the concept of disability, traditionally literature has tended to reinforce attitudes of condescension, dominance over, ambivalence and fear about physiological or mental difference (Couser 2002, 109-110; Davis 1998, 330; McDonagh 2000, 50; Mitchell & Snyder 205-209). On the other hand, literature has the capacity to do much more than pander to the status quo. We know that powerful narratives challenge cultural complacency and can be downright ‘subversive’ of popular beliefs (Bruner 1993, 136; 2002, 11; Peckham 228), and they also contribute to a record of the past that can help predict the future (Mar & Oatley 177).



## **Fiction and Nonfiction**

Some literary theorists devote considerable effort to articulating a boundary between fiction and nonfiction narratives. Best-seller lists make this distinction seem deceptively simple; however, if authors are moved to write stories that are inspired by personal experience, at what point does fiction become autobiographical? For that matter, to what extent are nonfiction texts influenced by the author's selection of what 'facts' to emphasize and overlook in order to make the narrative interesting or meaningful? When does history or biography become a story that may be largely fictitious from another's perspective? Bruner says that "[w]e know in our bones that stories are *made*, not *found* in the world. But we can't resist doubting it. Does art copy life, life art, or is it a two-way street? Even with fiction we wonder what a story is based on, as if it could not really be just made up" (2002, 22; emphasis in original). Is a true story necessarily one that can be documented as having actually occurred?

Fictional literature is defined by Mar and Oatley as a genre that allows the reader to approach "distant worlds that would otherwise remain unknown. Fictional stories not only allow us access to environments and situations that are difficult to experience firsthand, such as faraway countries and cultures, but it [sic.] also takes us to places that are impossible to reach, such as past societies" (181). If George Whalley is correct in his assertion that literature, by its very nature, "is the opposite of an escape: imagination is a realising-process, making the world real, making us real"(199), the escape that it does provide is from the limitations of our own experience. Reading fiction allows the reader access to worlds and experiences that would otherwise remain foreign.

Mar and Oatley's theory of fiction argues that "literary fiction is largely about people and the problems that arise when their desires, emotions, and goals come into conflict. We are attracted to literature because we are social creatures who are interested in one another" (182). While it may be true that works of fiction have the capacity to "leave us feeling that we know what we may never have seen" (Iyer 127), this explanation for the attraction of fiction does not necessarily distinguish it from nonfiction narratives, which often address the same concerns. Throughout their analysis, Mar and Oatley describe fiction as serving a unique social function, which could actually be ascribed to narrative more generally. For example, fiction is described as

a laboratory that allows us to experiment in a controlled and safe manner with intentions, emotions, and emotion-evoking situations that would be impossible and often highly undesirable in the real world. In narrative fiction, we can explore what it would be like to be a participant in a war for example, without the risk of injury or posttraumatic stress disorder. (183)

Unfortunately the authors do not make clear how a fictional account of being in a war offers a vicarious experience of combat that other types of narrative would not.

This position might make sense if the authors took a philosophical stance that all representations are ultimately fictions, which is the view held by Morse Peckham. He asserts that "[t]he definition of whether a discourse is fictive or non-fictive is... a matter of someone's judgment. And indeed the history of science itself is filled with statements originally judged to be non-fictive but now judged to be fictive" (224). However, this is not Mar and Oatley's view, as they do take pains to distinguish fictional narrative from other kinds of discourse. In this case, they argue that "reading purely expository nonnarrative accounts of a war in charts and tables of death tolls does not have the same

effect” (183). What they seem to be implying is that only fiction can be communicated through narrative.

This is a very narrow interpretation of narrative that is not widely shared by theorists across a range of academic disciplines, including Bruner, who explains that a “narrative models not only a world but the minds seeking to give it its meanings. And this restless dualism is not confined to drama and fiction: it also plagues the lawyer telling his law stories and the autobiographer trying to construct a self” (2002, 27).

Comprehensive historical accounts, documentary journalism, editorials, and internet blogs are all categories of nonfiction narrative that can have an emotional impact on readers, an impact that may even be more compelling because these narratives are assumed to be true.

For some, autobiography represents a particularly contentious genre for locating true stories. Couser (2002) quotes James Olney, who says that “‘autobiography-- the story of a distinctive culture written in individual characters and from within—offers a privileged access to an experience... that no other variety of writing can offer’” (109). Bruner agrees, but also cautions that “no autobiographer is ever free from questions about which self his autobiography is about, composed from what perspective, for whom. The one we write is only one *version*, one way of achieving coherence” (2002, 74; emphasis in original). Similarly, when a narrator sets out to tell any ‘true’ story, that truth is represented through the lens of one perspective that is determined by only those details remembered and selected for telling and, according to Andrew Scull, “all memory is built upon a foundation of forgetfulness (a forgetfulness, one must add, that is anything but random)” (6). Cognitive anthropologists believe that the selectivity of memory is more than a matter of conscious manipulation undertaken to tell one’s story in a way perceived

by the narrator as most fitting for the occasion. William J. Dewan cites Robert Schrauf, who argues that

recollections of past memories are not mental copies of stored originals. Rather, they are schematized, mental reconstructions of past events that are reassembled in particular circumstances for particular purposes... The cognitive analysis of autobiographical memories reveals several key elements: 'Recollection of the personal past is (1) essentially a reconstruction of the past, (2) prompted by a person's affective states and ongoing beliefs and goals, and (3) constituted by the sociocultural world of the rememberer'. (188)

Thus, the stories of our lives that we tell may be true, but that does not mean they are complete or incontrovertible.

In some cases, autobiography is a particularly important genre for countering the self that is socially constructed from the outside (Bruner 2002, 100). In fact, a number of terms are used in reference to stories told about the self. Along with autobiography, narrators refer to life history (Di Terlizzi 501), life writing (Couser 2006, 399), and life narrative, which for Sacks (1998) is "an inner narrative—whose continuity, whose sense, *is* our lives. It might be said that each of us constructs and lives, a 'narrative', and that this narrative *is* us, our identities" (110; emphasis in original). Irene Rose, also chooses to refer to the life narrative that she understands as a genre that may

include traditional autobiography, but work[s] to unseat the master narrative of the 'sovereign self' that traditional autobiography elevates. The concept thereby recognizes a wide variety of autobiographical textual forms and prompts investigation into the component parts of autobiographical acts and the cultural sites and structures that motivate their telling. (44)

Couser, Di Terlizzi and Rose all believe that these genres offer the potential for a less restrictive, sometimes less structured narrative medium that creates a space for people with some kinds of disabilities to have voice outside the typically narrow and, arguably, exclusionary criteria typically employed in determining what counts as literature (Manguel 124-125; Wellek 16-17).

Disability studies rely heavily on the autobiographical account to interrogate assumptions about disability, which have been heavily influenced by fictional representations that both shape and reflect how society views individuals with disabilities (Iyer 127), along with a medical perspective that tends to perceive the life of a person with disabilities exclusively in relation to the impairment. Thus, Couser (2008) observes that “[a]utobiography is a particularly important form of life writing about illness and disability because by definition it involves self-representation” (352). This kind of counter-narrative has a strong tradition in feminist scholarship and other minority discourses that challenge the qualifications of experts who do not share the identity of the subject populations that they write about.

The integration of minority discourses into mainstream publishing has also contributed to growing awareness within the medical community that it does not serve the ends of science or humanity to attempt to separate disease or disability from the lives that contain it. Oliver Sacks is a neurologist who gained renown for publishing biographical narratives about his patients in order to demonstrate the complexity of their clinical diagnoses and contextualizing disability as an aspect of life. He claims, categorically, that “the on-going nature of neurotic illness and its treatment cannot be displayed *except* by biography” (1990, 229; emphasis in original). As Sacks identifies the essential

function of biographical narrative to make the practice of medicine effective, Bruner makes a similar case in relation to fictional narrative and law:

Writs were hardly ever isolated from the way people in general viewed the nature of an orderly (or disorderly) world. The conditions they dealt with also found expression in literature, not just in the novels of Dickens or Trollope or in Blake's *Songs of Experience* but in newspaper stories and tavern tales.

Eventually these voices also found their way into the *corpus juris*, much as the narrative voices of the Harlem Renaissance or the 'reality' of Harriet Beecher Stowe's *Uncle Tom's Cabin* crept into the body of American law. (2002, 59-60)

Bruner demonstrates how cultural narratives contribute to legitimizing a legal system, as Sacks argues that personal narratives should direct how doctors treat a person with a disabling condition. A necessary tension can be seen to exist between stories and other discourses: scientific, legal, and political. The authority of law and medicine is disseminated, and challenged or sanctioned through both nonfiction and fictional narratives.

Mar and Oatley offer an explanation for the function of narrative in fields of law and science where advocacy is undertaken on behalf of a treatment, or a decision outside the realm of common practice. They believe that "fictional stories may be especially persuasive for those who hold strong countervailing attitudes, because the ideas embedded in a story are implied rather than explicitly stated, and the simulation demanded by stories leaves few resources for counterarguing" (84). No evidence is cited to support this claim, thereby leaving unarticulated an equally plausible counter-claim that many other people will read a story about values or ideals that oppose their own and

simply dismiss it as a bad story. If fiction can persuade, surely it also has the capacity to afford the reader an ‘out’ by being able to say in the end that it was not a ‘true’ story.

It is interesting that Mar and Oatley decline to elaborate on the function of life narratives on the grounds that this would not be “appropriate” in a paper devoted to “literary narrative” (184). This raises the question about how life narratives can be so summarily excluded from what is literary. The answer may be found in their definition of life narrative, which contrasts sharply with Couser’s and demonstrates the interpretive judgment (or bias) inherent in distinguishing what does and does not qualify as literature:

Life narratives and literary narratives are similar with regard to only the most superficial aspects, whereas the qualities of literature that make it most interesting (e.g., its careful construction and fictive imagining) do not apply to the stories we tell about our own lives. The simulative experience evoked by literature and the careful writing and rewriting that takes place during composition, including the construction of imagery-related tropes, are among the important and unique aspects of fiction literature... (Mar & Oatley 185).

This position is, arguably, rather hasty in its conclusion that life narratives and literary narratives are only “superficially” similar. Furthermore, the conclusion of this passage perpetuates Mar and Oatley’s tendency to categorize all literary narrative as fiction. What actually makes a story ring true may not necessarily determine its status as fiction or non-fiction.

Sacks offers an intriguing example that suggests that sometimes a fiction can be more ‘true’ than the event that inspired it. Harold Pinter wrote a play, *A Kind of Alaska*, based upon his reading of *Awakenings* eight years before. Sacks says that “Pinter had never seen my patients, nor even their images in the documentary of *Awakenings*; and

yet-- I was in total agreement with Margie—what he had written, uncannily, was just like the truth. ...I felt Pinter had somehow perceived more than I had written, had penetrated, divined, inexplicably into the heart of the matter, the inmost truth” (1990, 370). Many different representations of Sacks’ biographical case studies have been undertaken. His patients make fascinating subjects, yet the most meticulously researched efforts are not necessarily, in Sacks’ view, the most real or true. Returning to Pinter’s play, Sacks concludes that “[r]eality is conferred, re-conferred, by every original representation. I felt Pinter had given me as much as I gave him: I had given him a reality—and he had given me one back” (371). If nothing else, this illustration suggests that “truth” is not the exclusive terrain of either fictional or nonfiction narrative.

Just as fictional discourses may succeed in being true to life, critical readers should also be cautious about accepting nonfiction discourses at face value. The most simple distinction between fiction and nonfiction is determined by the author’s intention. Iyer claims that “the primary purpose of fiction is narration not instruction. The narrative is influenced not only by writers’ factual information but also by the story they want to tell” (127). This again implies a misleading assumption about fiction and nonfiction. A culture’s myths and fairytales were intended to instruct as well as entertain, and many nonfiction accounts tell beautiful stories.

Furthermore, narrators are not neutral observers of the phenomena they describe, or re-construct. The criteria for truth are inevitably shaped by the experience and expectations of the author (Harding 383-388; Howe 520-521; Irving 33-34; Murphy 157; Scholes 248; Yanow 2000, 60). In turn, the reader’s experience will determine the extent to which she or he accepts the representation as true: “[to] the extent that a work of literature points toward our experience as living human beings, we may value it for what



we call its ‘truth’ or ‘rightness’” (Scholes 248). This is the nature of the relationship between the narrator and his or her audience.

Bruner (2002) argues that “[t]he human mind, however cultivated its memory or refined its recording systems, can never fully and faithfully recapture the past, but neither can it escape from it. Memory and imagination supply and consume each other’s wares” (93). This is why any ‘true story’ can be contested; but what is more significant is how the interplay of the fictional narrative and the recall it stimulates in the reader may culminate in a reading that creates the potential for individual growth and change.

Mar and Oatley argue that “individuals who have been exposed to more fictional literature tend to exhibit better empathic abilities” (182). This view is re-affirmed by Ted Cohen, who believes that “[t]here is a connection... between the ability to fully appreciate narrative fiction and the ability to participate in the morality of life, precisely because the ability to imagine oneself to be someone else is a prerequisite for both” (73). This is facilitated, in part, through the way people process their own life stories in order to give their lives unity and purpose. Of course, the ability to imagine oneself as another is not the exclusive purview of fiction. At the same time, not all people who read fiction are particularly moral, and many people who will never read a novel still possess an innate sensitivity to the needs of others. However, reading widely may enhance whatever existing capacity for empathy resides within the individual. Cohen also says that “[s]tories move us, excite us, instruct us, and, in the first instance, in the dynamics of this effect, it does not seem to matter whether the story is thought to be true” (27). The plausibility of a narrative: the extent that the reader believes that it *could* be true, may be more important in story-telling than whatever experiences or flights of imagination inform the narrative.

## Narrative and Story

Narrative and story are both terms that are comprehensive enough to bridge fiction and nonfiction categories of discourse. For example, Bruner observes that “the medium of narrative [is] a form that keeps perpetually in play the uneasy alliance between the historically established and the imaginatively possible” (2002, 62). In another paper he explicitly defines story in similar terms: “[s]tory, whether purportedly real or fictive, requires temporary suspension of disbelief, but because at the end it will not be fully verifiable, it must justify this suspension by exhibiting verisimilitude” (1993, 134). Given that story is also used to refer to fiction and nonfiction discourses across a range of cultural and professional domains (Applegate 142; Couser 2007, 166; Goldstein 30; Lyle & Gehart para. 23; Malacrida 400; Neysmith, Bezanon & O’Connell 19; Pechter 51; Riessman & Quinney 393; Roe 9; Sacks 1990, viii; Yanow 57-58), it is notable that it is much less commonly identified as a concept in literary criticism.

While most literary critics address their analysis to narrative instead of story, Kenneth Burke is a rhetorician who does theorize about story, albeit not as a concept distinct from narrative. He designates story as a “realm of symbolic action, a realm that duplicates the realm of non-symbolic motion, but is not reducible to it (though not possible without it)” (43). Burke begins with the observation that language evolved as a system for imitating memory; that we experience the world through our senses and memory stores these sensations. Thus, “the *taste* of an orange is a sensation. The *words* ‘the taste of an orange’ tell a story” (43; emphasis in original). Others who understand story as a more complex structure, containing a beginning middle and end, might argue that Burke is merely suggesting a genesis for story. His theory of story is essentially

about how language makes the concept possible. Burke proceeds to write about story as a tool unique to humanity: “[b]y this resource, which adds narration to speechless nature, there arise in time stories of the Supernatural, or astrology, astronomy, alchemy, chemistry, geology, biology, geography, history, myths and rituals, ideologies and routines etc.” (43). From this perspective, it would appear that virtually all narrative and expository texts can be accommodated within the category of story.

Mar and Oatley introduce a more specific concept that they refer to as “literary stories”, which they define just about as broadly, as “simulations of selves in the social world” (173). The implication seems to be that there are other kinds of stories that are not literary, but their analysis does not clearly articulate what these other types of stories may be. However, the cohesiveness of the narrative is clearly a fundamental criterion:

everything included in the story is relevant and... all the elements of a story are coherent ... Aristotle...made such an observation in *Poetics*, noting that each constituent of a narrative should be integral to the whole so that any removal or reordering would disrupt the representation. Coherence is thus a defining feature of narratives. (176)

Mar and Oatley’s definition does not distinguish story as a particular *kind* of narrative, as throughout their paper they use the terms story and narrative interchangeably, without qualification or explanation.

At the same time however, they do identify literature as a distinct category of narrative: “[w]ith respect to the various instantiations of narrative, literature is unusual. It could be considered the most abstract of narrative forms, providing readers with a purely symbolic and nonrepresentational portrayal of the social world and its intentional agents” (186). It is unclear what literature is if it is “nonrepresentational,” but yet

“symbolic.” Symbols must represent something (Yanow 14). In their explanation Mar and Oatley, are separating literature from other narrative forms that have visual and auditory interpretational cues, such as dramatic interpretations on stage and screen (Mar & Oatley 173), yet all of these narrative genres still aspire to communicate a story.

Riessman and Quinney express frustration that narrative has “come to mean anything and everything” and they remind the reader that “[a]ll talk and text are not narrative. Developing a detailed plot, character, and the complexities of a setting are not needed in many communicative exchanges” (393). These are similar to the criteria that many other literary theorists use to describe story (Bruner 2002, 16-17; Goldstein 30; Kaplan 172; Mar & Oatley 174; Roe 36; Yanow 57-58). This apparent fluidity in the language of literary discourse may not be an outcome of careless writing. In Bruner’s 1993 essay, he takes pains to communicate how he deliberately chooses his terms:

I use the word ‘story’ advisedly. For that seems to be how human beings use their minds when faced with cultural-personal matters. We are given every cultural encouragement to do so, to encode in narrative. For the narrative is our natural as well as our conventional way for dealing with issues involving intentional states, desires, values, negotiations, and so on. (133)

Here story is a deliberately chosen concept, which Bruner then proceeds to define as narrative. Again, story is offered as a synonym for narrative, rather than a distinct category of narrative.

However, in a subsequent publication Bruner does qualify this position somewhat when he asks: “Do we need another book about narrative, about stories, what they are and how they are used?” (2002, 3). Here he understands story as a ‘form’ of narrative, albeit a form that seems to be quite flexible:

[w]e know that narrative in all its forms is a dialectic between what is expected and what came to pass. For there to be a story, something unforeseen must happen. Story is enormously sensitive to whatever challenges our conception of the canonical. It is an instrument not so much for solving problems as for finding them. The plight depicted marks a story's type as much as the resolution. We more often tell stories to forewarn than to instruct. And because of this, stories are a culture's coin and currency. (2002, 15)

In this passage Bruner seems to be suggesting that a narrative may constitute a story on the basis of the single criterion of something unexpected occurring: what Aristotle referred to as *peripeteia* (Bruner 2002, 16-17), which is translated in some editions as a reversal (Aristotle 50).

Dvora Yanow explores a method of interpretive policy analysis that draws upon narrative and story. She does distinguish between the concepts by explaining that “[n]arrative’ focuses on structures and sequences: what meanings, made by whom, with what congruences and conflicts among them? ‘Story’ focuses on plot and on the acts of telling and hearing—on intentions and attentions—helping policy analysts explore relationships between language and action” (61). It is not an entirely satisfying distinction, as it is problematic to understand how “plot and the acts of telling and hearing” can be understood separately from “structures and sequences”. Still, Yanow’s definition does stand out as an attempt to distinguish between concepts that many other theorists use interchangeably.

Emery Roe is another policy theorist who deliberately identifies story as a distinct narrative category. He explicitly states that “stories are not the only kind of narrative”(3), and proceeds to support his claim in relation to narrative policy analysis by asserting that:

“there are also nonstories, counterstories and metanarratives. The analyst’s second step is to identify those other narratives in the issues that do not conform to the definition of story or that run counter to the controversy’s dominant policy narratives. The former I call *nonstories*; the latter, *counterstories*” (3; emphasis in original). Roe does not clearly explain how counterstories and metanarratives are different from stories, although he defines the metanarrative as that which takes the polarized positions of a policy issue and “turns this polarization into another story altogether, one that is more pliable to policy intervention, however temporary that intervention may be”(4). Essentially, what Roe is doing here is creating categories to contain different *types* of stories rather than distinguishing between discourses that may be called stories, and those that are not .

Roe invokes Aristotle’s explanation of narrative cohesion in the *Poetics* by defining a nonstory as a “circular argument, for example, [which] has no beginning, middle, and end of its own”(3). However, not all stories are linear in their structure (Basting 26). Therefore, while it is fine to believe in ‘beginnings, middles and ends’ they do not necessarily need to occur in that order (Davenport 44; Pechter 48).

Writing from his experience as a policy analyst, Roe explains his narrative method through a series of case examples that he refers to as stories. At the same time, literary criticism does not generally seem interested in distinguishing between ‘narrative’ and ‘story’. However, in considering how other disciplines tend to employ these concepts it may be speculated that perhaps ‘story’ is a term that is most familiar in contexts where people are engaged in a direct or personal way with the narrative, rather than in terms of abstract theory or critical analysis. While it is difficult to find decisive evidence to support a preference for the term story over narrative to explain the discourses people generate about their lives, in every day language we do more typically say we ‘tell

stories', rather than 'tell narratives'. Parents tell their children 'bedtime stories', as opposed to 'bedtime narratives', which may communicate the intimacy of relationship generally experienced between teller and receiver of these narratives. In a similar vein, the word 'story' may also communicate greater personal attachment for a reader to a particular narrative. Bruner's answer to his question, "What, then, is a story?" (2002, 16) lends some credibility to this hypothesis when he answers his own question by moving from discussion of story as an abstract concept, to an analysis of a particular narrative that has personal meaning for him.

At the same time, we more typically refer to those narratives with which we are most intimately acquainted as our 'life story'. Pamela Cushing defines narratives as stories (161) and explains how "everyday narratives in L'Arche... function for sociability—either in relationship building, as humour, or as a way to give or elicit support from others. Another less explicit function of telling stories is to craft one's identity for others" (163). In a more formal professional context, it is not unusual for social workers to refer to client life stories that are shared within counseling relationships:

Stories we draw on in our clinical work are texts written by authors whose place in historical time, life experience, and personal proclivities shape both the plot of the story and the way it is originally told. Moreover, depending on our own interests, life histories, and dynamics both conscious and unconscious, we are attracted to certain stories more than others. (Applegate 142)

Again, the impression that story may suggest a more intimate and possibly informal relationship between reader and text, or narrator and audience is, admittedly, speculative because the comparative meaning and value of these concepts does not appear to have been deeply interrogated at a theoretical level.

In the end, whether we refer to narrative or story, they have the capacity to challenge the reader's personal assumptions about the world:

it may... be the case that transportation into a narrative can help us learn to empathize with types of individuals with whom we have no personal experience. For this reason, literature may be helpful for reducing bias against outgroup members. To comprehend such narrative fiction, we must acknowledge the common humanity present between ourselves and dissimilar others. Without the reader assuming the same (or similar) emotions, desires, and beliefs as the protagonist in the story, the phenomena of transportation, enjoyment, and ultimately understanding will remain elusive. (Mar & Oatley 181)

At the same time that a story has the capacity to transport the reader into new worlds of experience, the simultaneous distance that narrative affords allows the reader the security of a position of safety to better open herself up to empathy. This capacity for empathy is important if Bruner is correct in his belief that "great narrative is an invitation to problem finding, not a lesson in problem solving. It is deeply about plight, about the road rather than about the inn to which it leads" (2002, 20). The narrative provides the journey, the responses it may provoke depend upon the story's ability to move the reader, or listener. For when new stories are embraced by large numbers of readers-- or perhaps even a small number, provided those readers or listeners have significant power to influence-- the cultural values that determine social norms may undergo a shift: "Our stories, finally, may come to change the cultural world into which they are launched" (Bruner 1993, 136). In this way, new stories can revise dominant cultural narratives about all kinds of socially constructed categories, including disability.



### **CHAPTER 3- Disability Theory**

#### **What is Disability?**

When a reader considers Bruner's observation that "[t]here is now evidence that if we lacked the capacity to make stories about ourselves, there would be no such thing as selfhood" (2002, 86), what does this imply? Here Bruner is referring to one of Sacks' narratives about a patient with a syndrome that so severely impaired his memory that Sacks describes this patient as "scooped out, de-souled" (quid. in Bruner 2002, 86). Citing other critical theorists, Bruner concludes that "the construction of self-hood, it seems, cannot proceed without a capacity to narrate" (2002, 86). What are the implications of not being able to narrate one's own life story? Different theoretical models of disability influence responses to this question.

#### **Disability as Deficit and as an Aspect of Human Diversity**

Disability is sometimes conceptualized across a spectrum of theoretical frameworks ranging from models that see disability as a deficit contained within the individual that needs to be cured, or at least controlled, to a human rights model that constructs disability as simply another aspect of human diversity, such as gender, or ethnicity. Table 1 briefly describes a spectrum delineated by the Roeher Institute (1996), which can accommodate most theories of disability because these are not mutually exclusive categories, and many representations of disability are influenced by more than one paradigm.

**Table 1**

**Theoretical Frameworks of Disability**  
**← Disability as Deficit/ Disability as Diversity →**

<b>Moral</b>	<b>Medical</b>	<b>Functional</b>	<b>Environmental</b>	<b>Social Justice/Rights Outcome</b>
<ul style="list-style-type: none"> <li>• Seeks a religious, cultural or supernatural explanation for disability</li> <li>• A gift or a curse bestowed upon an individual or family</li> <li>• Disabled individual may be seen as responsible for his/her own condition</li> <li>• Perceptions may range from “God’s chosen ones” to “demon spawn”</li> </ul>	<ul style="list-style-type: none"> <li>• Emphasis on cure, or minimizing impairment, and prevention</li> <li>• Disability needs to be treated or managed via medical expertise</li> <li>• Doctors dominate care team including determinations around eligibility for home care and other services</li> </ul>	<ul style="list-style-type: none"> <li>• Emphasis on integrating the disabled individual into existing social networks</li> <li>• Promotion of ‘community living’ and ‘normalization’</li> <li>• Personal choice may be consulted but still primarily managed by professional expertise</li> <li>• Social assistance geared to supporting individual in existing environments</li> </ul>	<ul style="list-style-type: none"> <li>• Recognition that environmental structures and attitudes need to be adjusted to accommodate integration of disabled individuals</li> <li>• Advocates for accessible public spaces and transit services</li> <li>• Endorses policies that facilitate access to public spaces and programs that allow individuals to participate in the labour market</li> </ul>	<ul style="list-style-type: none"> <li>• Disability is as much a social construct as a physiological one</li> <li>• Disability is compounded by social stigma and ignorance similar to other marginalized populations</li> <li>• Disability as diversity, rather than personal deficit</li> <li>• All barriers are manifestations of discrimination</li> <li>• Emphasizes legal and political action</li> <li>• Institutional rather than individual change</li> </ul>

Moral models of disability predate scientific or systematic analysis of impairments that result in cognitive or physical differences from the mainstream population. Before the evolution of emancipatory theories regarding human rights, mythology and religion were the primary discourses for transmitting cultural values. In different places and times physical or mental deviance from the norm were associated with cultural taboos (Devlieger 1995); people were shunned, or perceived as “holy innocents” (McDonagh 1997, 270) that were worthy objects of charity. Today, at least in secular, Western societies, most moral and mystical explanations of disability come to us from mythology, religious parables and allegories. Margolis and Shapiro explain that “[t]he appearance of disabled characters in literature has its roots in mythology, the Bible, and fairytales. Mythical descriptions of disability are always essentially negative” (21). Although the assumptions that contributed to these explanations of disability are no longer dominant, vestiges of these beliefs may endure. Margolis and Shapiro, for instance, believe that classical representations of disability “are durable and remain in our memories long after the storyline is forgotten” (21). Further, they cite Bowe (1978) who asserts that “[o]ur memories of these and other characters often become indelible, impervious to any experiences we may have with disabled individuals in real life. Somewhere in the back of our minds we associate disabilities with sin, evil, and danger” (21). Certainly these ancient ideas about disability contributed to past attempts to cure people of their ‘madness’ via purging, sensory deprivation and aversion therapy that informed early medical intervention with mental disability (Scull 61).

Couser explains that disability has been typically represented as essentially an individual problem; and the medical model for defining and responding to disability has emphasized this perspective of individual bodily or cognitive deviance (2008, 354). The

medicalization of disability has, in many cases, contributed to the cure, prevention or management of many disabling conditions, thereby extending life expectancy and quality of life for many people. Medical models of disability are heavily invested in science and the perceived objective expertise of doctors. As a result, it is not surprising that, until relatively recently, very little has been recorded “about the perspectives and experiences of psychiatric patients” (Reaume ix) and other people with disabilities. Despite the curative intentions of medical science, many disabilities are chronic in nature and not necessarily the result of illness. Therefore, medical models, on their own, cannot satisfactorily account for the experience of disability.

Hand in hand with the curative objective of a medical model goes the promotion of functionalism: life-skills training and behaviour modification to make the person with disabilities resemble the mainstream population as much as possible (Roeher Institute 15). A central component of this framework is to implement life-skills programming where success “is measured by how closely people who use services can approximate the lives of ‘normal’ people” (Roeher Institute 15). This was the early objective of institutionalization in Ontario where the original intention was to rehabilitate and cure mental disability (Simmons 1982, 3). In reality, people with chronic disabilities often spent most of their lives in these facilities, or required supported community care. Still, the goal of functionalism is to promote the fullest degree of independent living that the individual can achieve. The operating assumption within functionalist theories of disability is that it is in every individual’s best interest to integrate into society as ‘normally’ as possible.

At the other end of the spectrum outlined in Table 1, emphasis moves increasingly from deficit-based theories to philosophies that perceive disability as a natural

manifestation of human diversity. Both environmental and social justice models of disability recognize that there is structural discrimination in the way that communities are built, which is disabling to many who navigate the world differently than the mainstream (Beresford & Croft 307-308; Dunn 424; Michalko 151; Sacks 1990, 228). This has generated advocacy that calls for raising public awareness and specifically calls for making public spaces accessible for all people. “The goal is to eliminate or modify environmental factors that hamper participation” (Roehrer Institute 16). In Ontario, this advocacy movement has brought about the passage of the Accessibility for Ontarians with Disabilities Act, 2005, which sets accessibility standards for public spaces, and deadlines for reaching them (I-1). Advocacy for environmental change entails calling for reconstruction of built spaces to promote accessibility for all people and make physiological diversity more visible in the community. While these are commendable objectives, some observe that they are most meaningful for people with physical disabilities. Eva Feder Kittay points out that “the impairment of mental retardation is not easily addressed by physical changes in the environment” (558). As a result, people with disabilities and their advocates are increasingly looking to a human-rights model to enforce their citizenship rights.

As people with disabilities and their advocates come to increasingly resist the interpretation of disability as exclusively an individual problem, the political dimension of disability is emphasized. Lobbying and campaigns to raise public awareness are undertaken in order to change policy that is perceived to have effectively excluded some members from actively participating in their communities: “The rights-outcome

approach<sup>1</sup> looks beyond particular environments to focus on broad systemic factors that keep certain people from participating as equals in society, and enable equality of well-being as an outcome” (Roeher Institute 17). Accessibility is no longer perceived as an issue of accommodation, but the entitlement of all citizens. Disability theorists, arguing from a human-rights perspective, assert that citizenship rights are being undermined because “[c]itizenship itself [is] increasingly conditional on conformity with the ideal, able, and employed individual who places no demands upon the fiscal resources of the state” (Chouinard & Crooks 31). The most radical expressions of the rights-outcome approach argue that it is the institutional systems that are ‘disabled’ for abrogating their responsibilities to a diverse citizenship.

Harlan Lane further criticizes what he refers to as “troubled-persons industries,” which he believes to have a vested interest in perpetuating the concept of disability as a problem that requires extensive professional oversight (81). Oliver agrees with this perspective, adding that

disability is structurally represented by the vocations of doctors and the para-medical professions, and we load responsibility for the restrictions that disabled people experience on to disabled people themselves, who are restricted because of the functional or psychological limitations imposed by their individual impairments rather than by the social restrictions imposed by society. (58)

In *Awakenings*, Sacks explains that this tendency to understand individuals exclusively in terms of their medical diagnosis “forecloses the possibility of learning anything new, and prevents the possibility of forming a picture, or pictures, of what it is like to be as one is” (1990, 225). Sacks is advocating for doctors to interact with patients in a way that is

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<sup>1</sup> More typically referred to as a social model of disability theory

similar to Goldstein's understanding of how social workers should engage with clients: "In assuming his or her role, the social worker surely is an expert about many things that need to be known or provided; the client, however, remains the expert about his or her reality, which includes the beliefs, values, culture, goals, and other subjective factors that give life meaning and purpose" (38). Especially in relation to people whose disability limits or precludes verbal communication, it is incumbent upon any doctor or social worker to know his or her client very well in order to bridge the divide between professional expertise on the science of the disorder, and the individual's expertise on his or her own life experience.

Medical and functional models of disability aspire to normalize the afflicted individual, and those services that promote a functional approach to ameliorating impairments tend to require extensive resources. For example, in his 1982 book about Ontario's institutional system, John Marshall includes an Appendix that depicts a training program for an individual to learn how to put on his own shirt in the morning. The procedure includes twelve steps. Step seven is broken down into thirteen parts. The one-on-one time that often needs to be invested in such programs is enormous, and not usually feasible in relation to the staffing complements of any supported living facility. Today, there is considerable debate within disability circles about whether this is the most effective investment of finite resources: Whose interests or priorities are paramount in pursuing a program of normalization? Should the emphasis be on assimilation or supporting cognitive difference?

Michalko believes that "[t]he 'natural inclination' to norm human life is what provides for the possibility of seeing any impairment as biology gone wrong. It also provides the impetus for seeing disabled people within the contemporary dichotomy of

the heroic and the tragic” (170). Of course, the existence of norms is dependent upon a corresponding understanding of what is abnormal or deviant. The Diagnostic and Statistical Manual (DSM) is a primary resource for doctors and other human services professionals for diagnosing abnormal human behaviours, but the science of the DSM needs to be challenged and revised on an ongoing basis. Geoffrey Nelson points out that the “DSM has both a cultural and gender bias with white, male, North American psychiatrists deciding who and what is viewed as ‘crazy’” (247). Crowe argues that the DSM-IV is encroaching into more and more aspects of people’s everyday lives (6); and Lewis agrees, asserting that half of all Americans will, at some point in their lives, meet the criteria of a DSM disorder (349).

The contemporary understanding of ‘normalcy’ is linked to an individual’s ability to be self-sufficient in a competitive, market economy: “A ‘normal’ citizen is first and foremost constructed as an individual participant in the labour market. This individual is also expected to translate his/her needs into market-oriented behaviour, for instance, conceiving of self as a care consumer in the market of caring services” (Neysmith, Bezanson & O’Connell, 13). Evolving in step with the Industrial Revolution, the science of normalcy began in the nineteenth century, with Adolphe Quetelet’s “notion of the normal as an imperative”, and the development of the branch of knowledge known as statistics that was incorporated to inform and justify state policy (Davis 1997, 11). Where once disability was generally unremarkable, and was even accommodated in small communities and extended kinship networks, it becomes politicized with the evolving social identity of the individual as worker and consumer.

The emphasis on economic productivity as normal makes many people with disabilities feel pressured to minimize the extent of their impairments in order to gain



economic security and social acceptance. Michalko finds that “[d]isabled people are heroic as long as we imitate the natural and the norm through our display of a commitment to it. So long as we act as if we are ‘normal people,’ albeit with an ‘abnormal biology,’ and so long as we adjust to this biology and do things, albeit differently, we are heroic” (171). At the same time, there are social sanctions attached to not aspiring to the heroic. J. Murphy observes that

[t]hose who claim discrimination at the marketplace or their jobs... are labeled as unprincipled and a threat to the common good. They are complainers who cannot deal with their failures and place their desires above those of society. Persons with disabilities are often viewed as complainers who cannot deal with the problems related to their disabilities. (161)

Given that people with disabilities already experience higher rates of unemployment than people without disabilities (Canadian Council on Social Development 6), and that labour force participation is an important determinant of happiness for people with disabilities (Uppal 530) there is strong incentive to try to adapt to cultural norms.

However, dominant cultural constructions of disability are being challenged in human rights policy, as well as other cultural texts. Because a “culture is partially constructed through ongoing, changing stories” (Cushing 166), some disability theorists argue that changes in the cultural construction of disability need to include a shift in the representational function of disability in literary narratives. David Mitchell and Sharon Snyder explain that “people with disabilities have been the object of representational treatments, but... their function in literary discourse is primarily twofold: disability pervades literary narrative, first, as a stock feature of characterization and, second, as an opportunistic metaphorical device” (205). Mitchell and Snyder refer to the literary

dependence upon disability metaphors and symbolism as “narrative prosthesis”: a narrative device that serves a symbolic or metaphorical role in narrative without challenging any of the conventional assumptions, or stereotypes surrounding disability (205-210). For example, Bertha Rochester fulfills the function of narrative prosthesis in Charlotte Brontë’s *Jane Eyre*. Her degenerate mind and bloated features further function to emphasize the heroine’s plain but unblemished figure, and a strong mind that masters passion.

One way to attempt to transcend stereotypical assumptions about a condition or category is to work to change the language associated with it. In order to challenge stereotypes attached to longstanding labels, efforts are often made to reform or update the language used to identify specific populations. However, changes in language do not necessarily correspond with changes in understanding about disability, or more inclusive attitudes toward diversity. A hundred years ago, it was considered entirely appropriate to assign people to services designed for idiots, imbeciles, the infirm, curably or incurably insane (Simmons 1982, xiv), according to a process of very arbitrary diagnosis (Reaume 28). Until the 1980s, advocacy groups and policy makers still designed services for the mentally retarded, which today is a term considered offensive by many people with mental disabilities and their advocates. In fact, Michael Prince finds that “[a]s recently as 2007, provincial laws contained such terms as ‘idiot’ and ‘moron’ to describe people with mental health conditions” (7). Realistically, defining disability is not so much dependent upon the words that are used, but more specifically on the cultural value attached to them.

Saussure’s principle about the arbitrary nature of the sign (1985, 37-38) is evident when the person once signified as “retarded” is now referred to as “challenged”, yet the signifier calls up the same concept. Language changes with regard to disability are

intended to communicate sensitivity toward difference and an enhanced spirit of inclusiveness, but John W. Murphy argues that this change in rhetoric typically represents a very superficial endorsement of social pluralism (154-161). Referring to people with disabilities as “challenged” does a disservice to people who face formidable obstacles in getting through their day-to-day lives. Everyone encounters challenges in life, but mine are not the same in kind or degree as someone who faces physical and social barriers in getting to school, holding a job, getting her daily care needs met, or being heard. As long as individuals and groups do not define *themselves*, it is likely that the ‘progressive’ nomenclature of today will be perceived as offensive at some point in the future.

Using language to attempt to diminish the negative associations attached to disability is to minimize differences between people who do not have disabling conditions and those who do. Not acknowledging disability, or embracing a ‘we’re all the same’ attitude toward physiological or mental impairment may be perceived as communicating an egalitarian philosophy. In reality, ignoring or being oblivious to disability does not destigmatize it. It may, in fact, actually compound oppression and marginalization. This sometimes becomes apparent where a strong identification with a specific disciplinary expertise leads to the presumption that the way of knowing that seems to be natural to oneself is necessarily natural to everyone. For example, Bruner finds that the capacity to narrate is a necessary condition of self-hood (2002, 86); and Ian Robinson argues that, “[i]t is *our* nature to think and to talk, and if we didn’t we wouldn’t be somehow pristinely natural, we’d be sub-human” (10; emphasis in original). This sort of limited awareness of the complexity of the human condition does not in itself constitute active discrimination. However, because of its prevalence, ignorance can perpetuate

stigmatization by people who have power and influence over others who are only equal in theory.

That being said, even disability researchers often look through a narrow lens when it comes to making pronouncements about the appropriate parameters of disability discourse. Simi Linton, for example, suggests that the “question of who ‘qualifies’ as disabled is as answerable or as confounding as questions about any identity status. One simple response might be that you are disabled if you say you are... The degree and significance of an individual’s impairment is often less of an issue than the degree to which someone identifies as disabled” (163). At first glance, this reads as an inclusive, empowering statement, but it does not take into account Bruner’s valid observation that identity is also constructed “from the outside in”. Many advocates continue to overlook a significant segment of the population of persons with mental disabilities when they assert, without qualification, that people with disabilities need to be the ones to determine the parameters of disability discourses. As Eva Feder Kittay points out, “[m]any people with mental retardation, especially when it is severe or profound or compounded by other disabilities, have been unaffected by the important strides made by other people with disabilities... Of all disabled people, the severely mentally retarded have least benefited from the inclusion fought for by the disability community” (558). This exclusion is apparent in Davis’ introduction to his *Disability Studies Reader* where he celebrates the evolution of the disability movement: “there have been people with disabilities throughout history, but it has only been in the last twenty years that one-armed people, quadriplegics, the blind, people with chronic diseases, and so on, have seen themselves as a single, allied, united physical minority” (2006, xvi). Where are the people with mental disabilities with severe communication impairments that preclude their active

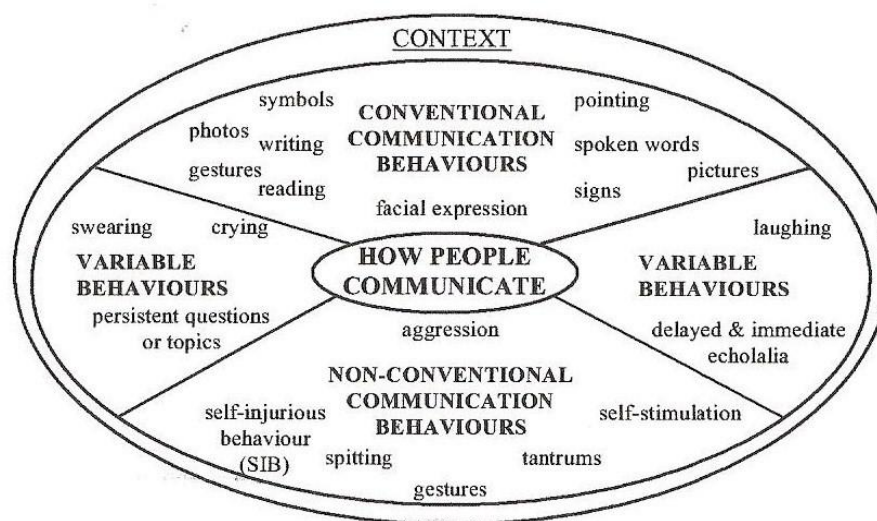
participation in this alliance? Presumably, they are included in the “and so on”. These are the people who will never have the option of speaking for themselves.

Unfortunately, communication barriers that exist for people with certain mental impairments leaves them very vulnerable to exploitation and abuse. For example, in his historical analysis of institutional life at the Toronto Hospital for the Insane, Geoffrey Reaume finds that, “[p]atients who were unable to communicate their needs to staff because of their mental disturbance, lack of verbal skills, or ‘incoherence’ to those around them would have been far more disadvantaged and frustrated in relations with staff, even to the point of being terrified, as they were truly alone in trying to make themselves understood” (75). However, despite the challenges of generating a counter-narrative to the perspectives of professional care-givers, personal relations and advocates, it is important to realize that, whether or not we can articulate a narrative, all people communicate in some way.

Jean Vanier has devoted his life to creating L’Arche communities of people who have profound intellectual disabilities, and he writes of many of the friendships he has formed with their members. For instance, he tells of a woman, Ghadir, who “suffered from cerebral palsy and couldn’t speak, but her smile, her trust, and her shining eyes welcomed me each time I came. Through her body, she ‘spoke’ so lovingly” (Vanier 37). The Habilitative Mental Health Resource Network (2002) has developed a model that conceptualizes the range of ways that people may express themselves, outside of narrative (Figure 2). Professionals who are committed to working *for* people with mental disabilities need to take on the commitment of learning how their clients, patients and service users communicate.

At the same time, the human mind has the capacity to compensate remarkably for places in the brain that are devastatingly damaged in ways that impair the ability to use language to communicate. People with profound mental disabilities may not be able to contemplate a past or imagine the future in an articulate way. However, they may live

**Fig. 2 Categories of Communication Behaviours**



intensely in the present. Sacks describes the “world of the simple” as populated by people who live a more “concrete” reality: “their world is vivid, intense, detailed, yet simple, precisely because it is concrete: neither complicated, diluted, nor unified, by abstraction” (1998, 174). Sacks further believes that this concrete sensibility does not preclude a capacity to experience that reality in a very rich and deep way:

The concrete is readily imbued with feeling and meaning—more readily, perhaps, than any abstract conception. It readily moves into the aesthetic, the dramatic, the comic, the symbolic, the whole wide deep world of art and spirit. *Conceptually*, then, mental defectives may be cripples—but in their powers of concrete and

symbolic apprehension they may be fully the equal of any ‘normal’ individual.

(Sacks 1998, 176-77; emphasis in original)

What this suggests is that the richness of a life experience, or a sense of self, is not necessarily dependent upon the ability to communicate one’s life narrative.

Bruner believes that selfhood is constructed as much from the outside in— by the way individuals are perceived by their culture— as it is from the inside out. He concludes that

[w]e gain the self-told narratives that make and remake our selves from the culture in which we live. However much we may rely on a functioning brain to achieve our selfhood, we are virtually from the start expressions of the culture that nurtures us. And culture is itself a dialectic, replete with alternative narratives about what self is or might be. The stories we tell to create ourselves reflect this dialectic.

(2002, 87)

This statement reaffirms the unstable status of disability as a concept or category of cultural identity, as it also reiterates Bruner’s understanding of language as a condition of selfhood.

Bruner’s epistemological assumption that language is a pre-condition of selfhood is similar to Whalley’s even more restrictive assumption that literacy is a universal condition (134). Both theorists are deeply immersed in a specific area of expertise that impairs their ability to see clearly beyond their disciplinary borders. Margaret Somerville is a scientist and ethicist who cautions that “[i]f, as many philosophers and others believe, language is fundamental to being human—fundamental to becoming fully our ‘self’, relating to others, experiencing our world, and finding meaning in life—then we must take great care in using it” (75). Later she affirms that language is important to

articulating a shared human reality; however, she also believes that making language a fundamental aspect of being human, or a requisite condition of an understanding of self has been a preoccupation largely confined to “the territory, the province, and the function of academics, scholars, and intellectuals, especially philosophers” (90). The ability to express relationship with others and impact the world can also be communicated in other ways.

This may be observed in the unreserved spontaneity and open emotion often communicated by some nonverbal people. Kittay argues that

[i]f personhood is limited to those who possess certain intellectual capacities and to those who are productive, then my daughter would not be a person. But my daughter is a person. She is, after all, my daughter. How can she be anything but a person? If traditional conceptions of personhood are not capacious enough to include Sesha and those who share her impairments, we need a new definition. I propose that being a person means having the capacity to be in certain relationships with other persons, to sustain contact with other persons, to shape one’s own world and the world of others, and to have a life that another person can conceive of as an imaginative possibility for him- or herself. (568)

Sacks affirms that it is our relations with other people that “carry the possibilities of proper being-in-the-world” (1990, 272) and give meaning to life. It may be discrimination based on disability, or ableism (J. Murphy 161), to argue that the capacity for narrative is a necessary pre-requisite for the construction of self. Perhaps academics, storytellers and advocates might enhance their contribution to their respective vocations by striving to observe more closely, inquire more directly, and imagine more vividly a human way of being that we cannot experience first-hand.



## **Intellectual Disability and Mental Illness**

The origin of distinct spheres of disability and mental health policy in Ontario has had at least as much to do with politics and the desire to establish the legitimacy of an emerging psychiatric profession as it has with scientific distinctions between the “curable and incurable insane” (Simmons 1982, 24). Psychiatry, and the medical profession generally, had a vested interest in populating the new asylums with “defectives” who could be potentially cured and returned as productive members of society, thereby raising the status of a new branch of medicine (Scull 120-123). As a result, those identified as mentally ill (or curably insane) went to the asylum, and the mentally retarded (incurables) were transferred to the institutional hospitals. However, Geoffrey Reaume’s research of patient files from the Provincial Lunatic Asylum (PLA) reveals that the facility housed a population of patients with overwhelmingly chronic conditions:

In 1876 it was estimated that seven-eighths of the asylum population were chronic and at the turn of the century it was estimated that 81.5 per cent of all admissions to 999 [Queen Street West] were in this category. By 1940, over 85 per cent of patients at the Toronto Hospital for the Insane were not considered fit for discharge, indicating that chronic care was the primary feature of the patient population. (7)

Simmons’ historical research on mental health policy in Ontario further affirms that “mentally retarded people still continued to find their way into the PLA. One reason was that local doctors were ignorant of any distinction between mental retardation and mental illness, lumping both together under the category of lunatic” (1982, 6). From the beginning, the process of assignation was inconsistent and haphazard, in part because

asylums for the insane and hospitals for the retarded were over-crowded, and people were sent wherever a bed could be found (Simmons 1990, 4).

Contributing to the confusing assignment process was the fact that determinations about mental fitness often were often made in the courtroom where judges were called upon to decide who should be imprisoned and who should be institutionalized. “They had to choose between the prison and the hospital, two solutions that, in the final analysis, were somewhat equivalent. The problem was: This individual needs to be locked up” (Foucault Roundtable, 85). Simmons also finds that “some scholars have argued that many of those labeled as mentally ill suffered from nothing more than a tendency to depart from accepted political or social norms and that the function of these hospitals was to impose social control over these deviants” (1990, 4). These facilities were also sometimes a refuge for people who needed to escape from their families (Reaume 24), or people who simply had no other personal supports.

Although the asylums for the ‘curably insane’ tended to be better funded than the institutions for people deemed to have little prospect of recovery, both systems were chronically underfunded; therefore, the ability to pay also could influence patient placement. The class system that was prevalent in wider society was reproduced within the institution (Reaume 9). Regardless of their prospects for cure, patients who had financial support were more likely to be placed in the insane asylum, rather than the facility in Orillia that was designated for idiots (Simmons 1982, 22-23) because a better quality of life could be purchased there. The arbitrary assignment of people deemed mentally ill or mentally retarded is further supported by Reaume’s finding that patients were exchanged between the asylums for lunatics and hospitals for the feeble-minded based upon their capacity to supply specific types of labour to support the facility,

whatever the individual's diagnosis (153). He gives several examples including the case of Wilfred S. who was "presented at a medical conference to determine whether he was suitable to be sent as a worker to a 'bush farm' at the Orillia Hospital for the Feeble Minded. He was transferred there in 1911 after 14 years at 999" (153). This individual did not suddenly convert from being mentally ill to mentally retarded; he was transferred for his worth as unpaid labour. Reaume and Simmons both cite evidence that suggests that the labour needs of the asylum and hospital systems often influenced diagnosis and patient placement.

Given the political interests that have influenced diagnosis and treatment of mental illness and disability, it is hardly surprising that many people have become skeptical about the methods for curing the mentally ill, or even the validity of these categories. Dvora Yanow explains that "[t]he conceptual logic of category-making implies that the differences between members of different categories are sharp, when from another viewpoint they may be only minor gradations of difference" (50). Certainly, many people who identify themselves as psychiatric survivors maintain that mental illness is not a legitimate category. Bradley Lewis asserts that "[m]ental illness is not an objective medical reality but rather either a negative label or a strategy for coping in a mad world" (343). Lewis cites the work of Thomas Szasz, who trained as a psychiatrist only to eventually devote his career to proving its illegitimacy:

For Szasz, *physical illness* was real because it was based on actual observation, but *mental illness* was at best a metaphor. A broken leg is real because you can see the x-ray, but a 'broken brain' is a myth because there is no x-ray that will show it. For Szasz, to see mental illness as 'real' rather than as metaphor was to make a serious category mistake. 'Mental illness' is not objectively observable; it is a myth.

(Lewis 343; emphasis in original)

In reality, many people are service users of both mental health and disability services because people with chronic mental illness or intellectual disabilities often require similar services and supports.

Today, the diagnostic criteria used to determine who is streamed into which administrative system are still haphazard. There remains a lack of clarity around the eligibility for mental health or disability services in Ontario which, since the 1970s, have fallen under the auspices of ministries that are known today as the Ministry of Health and Long-Term Care, and the Ministry of Community and Social Services, respectively. There are separate eligibility criteria for programs and services under each Ministry, yet there is obvious overlap in terms of how mental illness and disability are defined. For example, the Mental Health Act, which is administered by the Ministry of Health and Long-Term Care, defines “mental disorder” as “any disease or disability of the mind”(1.i). At the same time, the Government of Ontario, through the agency of the Minister of Community and Social Services, has proclaimed a new Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, which defines developmental disability in terms of a person who has

prescribed significant limitations in cognitive functioning and adaptive functioning and those limitations (a) originated before the person reached 18 years of age; (b) are likely to be life-long in nature; and (c) affect areas of major life activity, such as personal care, language skills, learning abilities, the capacity to live independently as an adult or any other prescribed activity. (3.1)

It is interesting that the policy definition of disability actually seems more dependent upon a medical model of specific diagnosis than does the policy definition of mental

illness. On the other hand, the definition of mental disorder seems to capture any and all manifestations of cognitive deviance from whatever is considered normal. Evidence of the historical distinction between “curable” and “incurable” insanity endures in the legislative stipulation that an intellectual disability be understood as life-long in nature.

Recently, however, there is an emerging preference for the term “recovery” in the field of mental health, which “is not the same thing as being cured. For many individuals, it is a way of living a satisfying, hopeful, and productive life even with limitations caused by the illness; for others, recovery means the reduction or complete remission of symptoms related to mental illness” (Kirby 42). This definition suggests a framework for understanding mental health that further blurs categories of illness and disability by recognizing that, at least for some people, mental illness is a chronic condition that is permanently disabling; and further, that “not everyone living with a mental illness will be able to recover” (Kirby 42). From recovery perspectives, emphasis is placed on advancing individual life planning and the provision of supports that are perceived to optimize and sustain mental health and a good quality of life, as defined by the individual and co-creators of his or her life narrative. A recovery model emphasizes wellness over illness (Baldwin qtd in Kirby 43). This position ultimately endorses policy frameworks and services that are very similar to those aspired to in contemporary disability theories that emphasize ability over impairment.

Still, contemporary writers generally maintain the distinction between illness and disability. Iyer alludes to it in relation to the depiction of intellectual disability in fiction, observing that, “[l]iterary depictions of intellectual disability and mental illness share some common themes. They both reflect societal views about these conditions in the time that they were written” (127). However, there is a richer narrative tradition of first-

person accounts of recovering from mental illness, while, on the other hand, “[i]ntellectual disability is fundamentally different in this respect because the very nature of the condition makes it difficult to have a subjective account of what it is to have it. In fictional accounts of people with intellectual disabilities, words are used to describe those who are essentially without access to the medium used to portray them” (127). While Iyer concisely identifies the challenge of narrating an experience that cannot be articulated from within, it is important not to perceive people with intellectual disabilities as a homogenous population; to assume, for example, that all people with intellectual disabilities are nonverbal.

Defining disability is no less problematic outside the realm of policy and program planning, especially for critics who take a particular interest in the representation of disability in literature. Patrick McDonagh theorizes about the representation of disability in literature, and he explains his rationale for selecting the term intellectual disability to define his subject category by acknowledging its limitations:

The idea of intellectual disability has never been without cultural meaning.

I use ‘intellectual disability’ because it is a contemporary term whose connotative powers are not so developed as other more pejorative terms: it simply carries less semiotic baggage. The proviso, of course, is that intelligence has no clear definition, nor is there any way to measure it. (1997, 268)

The lack of consensus around an appropriate and precise definition of intellectual disability only compounds the challenges associated with trying to distinguish between intellectual disability and mental illness.

Complicating the categorizing process further is the fact that many contemporary diagnoses do not easily fit into distinct disability or psychiatric categories. Autism

spectrum disorders are a good example. Hudson and Chan point out that there are significant limitations to the

definition of psychiatric disorder or mental illness that include autism spectrum disorder or similar syndromes. To include these syndromes as a psychiatric disorder is problematic in terms of service provision and treatment plans. There also appears to be a lack of common understanding between the definition of challenging behaviour as symptomatic of a person's behaviour or syndrome and challenging behaviour as a distinguishing feature of a psychiatric disorder. (34)

Across different disciplinary literatures autism is referred to as a disease (Ray-Mihm 102-103), a psychiatric disorder (Hudson & Chan 34), and as neurological difference (Bagatell 420). Lack of consensus around causes and appropriate responses must remind us that the boundary between disease and disability is a porous one.

Another reason why it is so difficult to establish a boundary between disability and illness is that there is so much diversity within each category, and sometimes similar symptoms are attributed to a range of diagnoses. In the absence of reliable diagnostic testing for many mental illnesses or disabilities, a field of critical psychiatry is emerging where "psychiatrists are moving beyond the narrow approaches of their training and drawing from interdisciplinary theory in science studies, disability studies, and the humanities" (Lewis 344). This approach helps fill knowledge gaps where patients face barriers to communicating a rich description of their symptoms and experiences. Tom Shakespeare agrees that it is important to consider the relationship between symptoms and the individual's quality of life, suggesting that

[i]f a person with multiple sclerosis is depressed, how easy is it to make a causal separation between the effect of the impairment itself; her reaction to having an

impairment; her reaction to being oppressed and excluded on the basis of having an impairment; other, unrelated reasons for her to be depressed? In practice, social and individual aspects are almost inextricable in the complexity of the lived experience of disability. (201)

In some cases, symptoms of the disability may mimic mental illness. In other cases those symptoms may actually indicate mental illness, but the diagnostic testing employed is not sophisticated enough to accommodate the communication methods of nonverbal people.

As Sacks readily admits, “our ‘evaluations’ are ridiculously inadequate” (1998, 181).

Although many mental health professionals suspect a close relationship between mental illness and disability it is very difficult to make a dual diagnosis when patients with intellectual disabilities have trouble describing their symptoms (Hudson & Chan, 41).

Even where there exists fairly substantial verbal capacity, the reliability of self-disclosure can often be problematic for making a sure diagnosis. There is significant evidence, for instance, that many people with intellectual impairments may be easily led by the interviewer. Interview subjects may be trying to guess what is the right answer, or just trying to be agreeable. Claudia Malacrida argues that

[i]ndividuals with intellectual disabilities may be especially vulnerable to...

discrediting strategies precisely because they are so devalued and stigmatized. For example, researchers have argued that individuals with intellectual disabilities are particularly prone to persuasion by researchers and therapists, particularly when claims of abuse have been involved. (406)

Malacrida believes that researchers and frontline workers regularly use this evidence as an excuse not to consult with people with intellectual disabilities about their experience, and she wants their ‘truths’ to be believed, without question. This is difficult interpretive



terrain, and the conscientious worker or researcher must tread cautiously to avoid manipulating messages being communicated by people with intellectual or mental health impairments. Professional praxis entails engaging in continuous action and reflection (Flyvbjerg 136; Friere 128). Such praxis needs to be exercised by social workers in order to avoid uncritically accepting responses that can be interpreted as consistent with the worker's own perspective, while dismissing those that seem unlikely or otherwise problematic.

If no definition of disability can contain all of its dimensions and interpretive perspectives, then perhaps it is prudent to take a simple but inclusive approach. The Canadian Charter of Rights and Freedoms collapses mental and physical categories in its definition of disability as a domain of protection from discrimination: "Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability" (Sec. 15.1). The Ontario Human Rights Code also recognizes the rights of people with disabilities to enjoy freedom from discrimination, incorporating a definition of disability that is consistent with and expands upon that delineated in the Charter:

'Disability' covers a broad range and degree of conditions, some visible and others not. A disability may have been present from birth, caused by accident, or developed over time. It includes, physical, mental and learning disabilities, mental disorders, hearing or vision disabilities, epilepsy, drug and alcohol dependencies, environmental sensitivities, as well as other conditions. (Ontario Human Rights Commission para. 5)

More recently, the Accessibility for Ontarians with Disabilities Act (2005) defines disability as:

- (a) any degree of physical disability, infirmity, malformation or disfigurement that is caused by bodily injury, birth defect or illness and, without limiting the generality of the foregoing, includes diabetes mellitus, epilepsy, a brain injury, any degree of paralysis, amputation, lack of physical co-ordination, blindness or visual impediment, deafness or hearing impediment, muteness or speech impediment, or physical reliance on a guide dog or other animal or on a wheelchair or other remedial appliance or device,
  - (b) a condition of mental impairment or a developmental disability,
  - (c) a learning disability, or a dysfunction in one or more of the processes involved in understanding or using symbols or spoken language,
  - (d) a mental disorder,
  - (e) an injury or disability for which benefits were claimed or received under the insurance plan established under the *Workplace Safety and Insurance Act, 1997*
- (I.2)

It is clear that when disability is defined in relation to human rights policy, the causes of disability are not relevant. Whether as a result of accident, genetic anomaly, or illness mental disability may manifest itself in ways that make it incumbent upon social workers and other advocates to organize, translate or co-create personal narratives. Regardless of the cause of impairment, these stories often contain thematic similarities in terms of personal aspirations and systemic barriers to realizing life goals or ‘happy endings’.

#### **CHAPTER 4- Policy Theory**

## **What is Policy and Planning?**

Policy is what governs our social existence through the implementation and enforcement of laws, regulations, programs and services that define a collective sense of reality. “As cultural scripts, policy documents communicate certain values, case specific roles, and convey particular models of people and communities” (Prince 7). According to Frank Fischer and John Forester, “if analysts’ ways of representing policy and planning issues must make assumptions about causality and responsibility, about legitimacy and authority, and about interests, needs, values, preferences and obligations, then the language of policy and planning analyses not only depicts but also constructs the issues at hand” (1). Like disability, policy and planning may be seen as unstable concepts, generating different interpretations at different times and across different theoretical perspectives.

Social policy is specifically intended to address problems resulting from unequal access to resources required to maintain health and well-being that, in turn, enable participation in one’s community. Traditionally, social policy has been understood to refer to a range of state programs, legislation and regulations focused on the well-being of citizens. In North America and Europe in the twentieth century, programs and certain laws were captured under the umbrella of the ‘welfare state’. Health, education, culture and income assistance or security initiatives have formed the substantive program arenas for most discussion of social policy. Economic policies are included in this list by some analysts... . (Neysmith et al. 21-22)

However, determining what constitutes a reasonable standard of care, a poverty line, or a basic social minimum to which all citizens should be entitled is a contentious field of

debate, and consensus around shared social values is elusive (Westhues 5-9). Therefore, it is not surprising that the representation of mental disability is no more consistent in policy, over time, than it is in other types of discourse, including narrative fiction.

Generally, policy and planning discourses differ from narratives in their construction. Thomas J. Kaplan explains that policy is typically expressed in accordance with a chronicle approach. He says that a “chronicle is usually terse and often takes the form of an outline or a list of pros and cons. The chronicle approach does not seek to tell a story, presents no plot, and exhibits no organized beginning, middle, or end” (173). This is, arguably, a rather narrow determination of what counts as policy, especially when policy may be understood as a category that incorporates discourses as large and complex as international charters and conventions, to the ambitious mission statement of a small community nonprofit organization. As Yanow observes, “policy-relevant groups interpret a wide range of acts, from agenda-setting acts to acts legislating and implementing, as communicating policy meaning” (74). Some policy discourses are invested with the force of law, while others are aspirational. In either case, policy texts are often quite expansive and even eloquent.

### **Systematic and Interpretive Policy and Planning Theories**

As with other knowledge disciplines, social policy embraces both systematic and interpretive theoretical approaches. Barclay Hudson (1979) introduced a model that depicts a continuum of different planning models that may be used for responding to social welfare issues (Table 2). The strengths and limitations of these planning approaches are defined under the SITAR acronym and, similar to the spectrum of disability theories articulated previously in Table 1, most planning traditions can be

accommodated within the SITAR model. These different approaches may be understood to represent contending frameworks that not only refer to different policy discourses, but also different courses of action, values and meanings (Yanow 12). The following discussion describes the contributing theoretical approaches that Hudson incorporates in his model, and then subsequently critiques them in terms of their implications for social policy planning, especially with regard to people with mental disabilities.

The synoptic approach to policy planning emphasizes a systematic model of means and ends. Also referred to as rational planning (Dewan 185; Flyvbjerg 15-34; Gilbert & Specht 72; Rothman & Zald 1985), it assumes the presence of inputs and outputs that can be measured and compared in order to arrive at the most efficient policy solution. Barclay Hudson explains that synoptic planning involves a process that “typically looks at problems from a systems viewpoint, using conceptual or mathematical models relating ends (objectives) to means (resources and constraints), with heavy reliance on numbers and quantitative analysis” (389). Synoptic, or rational planning methods have a long history in all branches of policy planning and administration; however, their limitations in terms of the provision of human services have also been widely recognized (Davidoff 1965; Etzioni 1977; Friedmann 1977; Healey 2005; Hudson 1979; Lindblom 1977, 1979; Rothman & Zald 133-135).

**Table 2****SITAR Model of Policy Planning**

<b>Synoptic</b>	<b>Incremental</b>	<b>Transactive</b>	<b>Advocacy</b>	<b>Radical</b>
<ul style="list-style-type: none"><li>• Also referred to as rational planning</li><li>• Emphasis on means and ends, mathematical models</li><li>• Planner as objective expert</li></ul>	<ul style="list-style-type: none"><li>• Belief that policy structures cannot tolerate radical change</li><li>• Change is made over time, through a series of stakeholder trade-offs, mutual adjustment</li><li>• Planning and implementation occur simultaneously</li></ul>	<ul style="list-style-type: none"><li>• Planning becomes decentralized</li><li>• Process- oriented with emphasis on mutual learning between planner and recipient of services</li><li>• Subjects of planning take more control of the process</li></ul>	<ul style="list-style-type: none"><li>• Planner identifies with the stakeholder and actively works on their behalf to realize desired policy change</li><li>• Promotes policy pluralism</li><li>• Challenges perception of unitary public interest</li></ul>	<ul style="list-style-type: none"><li>• Emphasis on personal growth and freedom from manipulation from government or other institutional forces</li><li>• Call for structural change, either incrementally or through revolutionary means</li></ul>

Competing stakeholder interests and the unpredictability of human behaviour means that rational planning can only be aspired to as an ideal. All policy, including social policy, is continually re-interpreted from the planning table and legislative assembly, through to the frontlines where it is finally operationalized. At this point, it often becomes apparent that “interpretations may be at odds with what policymakers (whether legislators or agency actors) intend to communicate” (Yanow 74). There are trade-offs at every level of administration as well as at the point of service delivery. Sometimes these adjustments are the outcome of deliberate negotiations, or responses to new information. At other times policy is just interpreted in unanticipated ways. The realities of human services administration and program delivery move many policy theorists to assert that, to the extent that policy changes, it can only deliberately do so incrementally:

Disjointed incrementalism involves choosing among a limited range of alternatives that differ in small degrees from existing policies... Unlike the rationalistic approach this model does not emphasize problem solving by in-depth analysis of cause-and-effect relationships and examination of all possible courses of action. Instead, the incremental approach seeks to achieve small remedial gains through successive limited comparisons between ‘what is’ and ‘what is acceptable or feasible in the way of change’. (Gilbert & Specht, 73-74)

Lindblom distinguishes between the realms of the policy theorist who has the luxury of thinking in terms of ideal states, and the practitioner who at any time has only a limited range of options to select from when responding to social welfare crises as they emerge, on the ground. Thus, the social planner practices the “science of muddling through”

(1977, 98; 1979, 517) because he or she realizes that whole-scale change within administrative systems is impossible.

Moving from an emphasis on planning outcomes to planning processes, Hudson acknowledges that the three remaining approaches in his SITAR model are more typically conceived as responses to dominant planning traditions, particularly the synoptic method. However, transactive, advocacy and radical planning practices are important because they introduce “a broader perspective on issues and another set of voices for articulating the public interest” (396). Beginning with transactive planning, this planning approach emphasizes a collaborative relationship between the professional helper and the client (Friedmann 113; Gilbert & Specht 74; Hudson 389). Constituents are consulted by planners regarding their own social welfare requirements in order to seek direction for progressive change. This is an aspect of Roe’s approach to narrative policy analysis, as he explains that “[t]he narrative policy analyst encourages marginalized voices in a controversy to speak up, to tell their own stories, on the grounds that the more policy narratives there are, the better idea about metanarratives, if any, they generate” (18). Moving away from the winner/loser dichotomy in a planning conflict, a transactive approach to planning is important because of new knowledge that can be generated by consulting the expertise of service recipients who are generally marginalized from traditional planning processes.

For example, although he does not use the term, Sacks demonstrates a transactive approach to planning a course of therapy for patients in his description of how the contributions of patients inform the physician’s understanding of their impairments:

[o]ne must drop all presuppositions and dogmas and rules—for these only lead to stalemate or disaster; one must cease to regard all patients as replicas, and honour



each one with individual attention, attention to how *he* is doing, to *his* individual reactions and propensities; and, in this way, with the patient as one's equal, one's co-explorer, not one's puppet, one may find therapeutic ways that are better than other ways, tactics which can be modified as the occasion requires. (1990, 259; emphasis in original)

This is reminiscent of Paulo Friere's exhortation for professional helpers to embrace a process of mutual learning in working with oppressed and disenfranchised populations. In providing education to poor and marginalized people, he says that "[t]he teacher is no longer merely the-one-who-teaches, but one who is himself taught in dialogue with the students, who in turn while being taught also teach. They become jointly responsible for a process in which all grow" (80). Friere explicitly acknowledges the expertise of these constituents; an expertise that planners, educators, or community organizers must not only acknowledge, but learn from in order to do their work well.

In moving from transactive to advocacy planning, it is evident that the two approaches share some theoretical ground; however, while advocacy planning may entail the active participation of individuals or groups directly affected by a policy proposal, this is not always the case. Advocacy planners use their expertise to work on behalf of identified constituency groups. Premised on a philosophy espousing that "[t]here are no neutral grounds for evaluating a plan; there are as many evaluative systems as there are value systems" (Davidoff 443), advocacy planners recognize that diverse constituencies require different supports to actively participate and contribute to their communities. People with severe mental disabilities and communication impairments may not be able to effectively participate in a transactive planning process. In these circumstances, an

advocacy model may be the most effective approach for realizing structural policy change, on their behalf.

Radical disability theorists take the advocate's critique of existing policy systems even further, arguing that institutional structures are responsible for the oppression of people within capitalist, patriarchal or colonial systems. People who see their political and economic systems as structurally flawed and disabling will seek to replace them, either by working from within the system to transform it, or outside of it through insurrection and revolution (Hudson 390).

Although the SITAR model acknowledges and even advocates for drawing from the strengths of the different contributing approaches to address particular policy issues, Hudson also makes reference to a method specifically identified in planning literature as mixed scanning (396). Mixed scanning recognizes the ideal of a rational approach to policy making that is objective and comprehensive, as well as the unpredictability of human behaviour that makes small, incremental policy adjustments in the day to day reality in administrative settings. Thus,

[m]ixed scanning attempts to incorporate the strengths of both [synoptic and incremental] theoretical approaches into a workable approach to planning that involves a combination of elements of the rationalistic model that emphasize the analytic tasks of research and fact-gathering and elements of the incremental approach that emphasize the interactional task of consensus building. (Gilbert & Specht 73)

Mixed scanning may be understood as an example of how different features of the theories that contribute to the SITAR model may be combined to address specific policy problems and planning issues. Jerome H. Kaufman's accompanying commentary on

Hudson's model extols the advantages of drawing from the contributing traditions to resolve specific policy issues: "[t]he SITAR acronym... is cleverly applied to planning... the five-string SITAR is a type of lute which can be played by performing a single string at a time, or by weaving a blend of harmony and dissonance from all five" (404). Features from the contributing theories can be combined in different ways to construct innovative and effective policy responses to human need generally, and supports for people with mental disabilities, specifically.

Those required supports can be substantial, ranging from daily assistance with personal care and mobility to facilitating community access, work and learning opportunities. People with mental disabilities experience higher rates of unemployment (Uppal 529), poverty (Nelson 258), ill health and housing insecurity than the population at large (Dunn 413-425); and J. Thomas Couser recognizes that "[s]o many controversial issues in the arenas of public policy and public culture are bound up with variations in the form or function of our bodies" (2008, 351). For these reasons, Dunn acknowledges that "[o]ne of the challenges of social policy is to respond to the needs of Canadians with disabilities in a comprehensive, just, and effective manner" (413). Such a response must entail reinforcing what Canadians understand as our social safety net: the network of policies coordinated between federal, provincial and municipal levels of government to provide services and supports to people in need.

The range of disability experience calls for social policy responses that are flexible and responsive to individual needs. Sacks articulates the limitations of a systematic approach by emphasizing how the life experiences of people cannot be rationally predicted or addressed in a uniform way. Thus, in his attempt to further illuminate the experience of disability, Sacks explains:

[m]y aim is not to make a system, or to see patients as systems, but to picture a world, a variety of worlds—the landscapes of being in which these patients reside. And the picturing of worlds requires not a static and systematic formulation, but an active exploration of images and views, a continual jumping-about and imaginative *movement*. (1990, xviii; emphasis in original)

Not only do synoptic planning goals take a long time to realize, rational social planning objectives are also based upon the assumption that human needs are predictable and consistent across and within designated categories such as age, income, culture and geographic location. Because rational planning goals are dependent upon the existence of objective facts, John W. Murphy argues that rational social policy outcomes may never be attained because

facts are not things—the hallmark of Durkheim’s stance on norms—but accomplishments... facts are acknowledged to be constructed consciously and maintained through continued interaction between persons. Facts, in other words, are a product of intentionality, and thus norms are not objective but revealed through on-going discourse. Those that become prominent are elevated in importance because of shifts in values, beliefs, or commitments. (157)

Beyond the basic necessities of life, there is little predictable enough about human behaviour to constitute objective facts. Even if these existed, Bruner notes that our systems of measurement make planning an imperfect science, at best, because

our plans sometimes fail not just because we don’t know enough but also because of the way we know things. And it is not just that we are ‘all too human’ and shape our knowledge to conform to our wishes and fears. We are not good statistical machines, and are prone to inferential errors. These are fulsomely

annotated in the literature on ‘human error tendencies’—errors in judging others, in making investment choices, in predicting outcomes generally. (2002, 29-30)

Here, Bruner agrees with Charles Lindblom who argues that any kind of strategic analysis must inevitably be incomplete because it is impossible to identify, measure and compare all the risks and benefits of all the different types of policy options that are theoretically available to the planner (1979, 518). Along with the limitations of the mind’s capacity to operate independent of values, the other great obstacle to practising a theory of rational planning in human services provision is that even people identified as belonging to a similar category of need may require different provisions to meet that need (Hillyard & Watson 332-333). As a result, large scale policy interventions generally need to be invested with a considerable degree of flexibility in order to fit individual case circumstances and be efficient.

The enhanced ability to accommodate emerging contingencies is a strength of the incremental approach to policy planning. However, accommodation via small incremental adjustment also has serious limitations, as Lindblom admits that one drawback of this approach is that it does not allow for consideration of policy alternatives that do not closely resemble the status quo (1977, 110). On the other hand, “when decisions are only incremental—closely related to known policies, it is easier... to make correction for injury already accomplished” (Lindblom 1977, 107-08). In the day to day world of administration what the planner really is trying to do is keep all the competing stakeholder interests in play and, at least to some degree, satisfied.

Transactive planning, with its emphasis on process rather than outcome, directly engages the planner with learning from the constituency that receives social welfare services, or is otherwise affected by policy intervention. However, participatory action

projects require a lot of collaboration of unique stakeholder interests and strong public support to realize significant change. As a result, participation in transactive policy planning efforts may be initially empowering for constituents who are invited to contribute their personal expertise at the planning table, but repeated experiences of opposition to changing the policy status quo in a meaningful way can ultimately compound the experience of marginalization.

Nelson delineates some of the key features of such an approach to service planning for the provision of services to people with mental health disabilities. His community process model goes hand in hand with transactive and advocacy planning ideals, and has specific implications for people with disabilities who require other people to represent their interests, at least to some extent:

First, not only is the consumer at the centre of the framework, but the consumer also controls and directs the sources of support that surround him or her. Second, while mental health services are part of the framework, there is a strong emphasis on other sources of support, including family, friends, social networks, peer support, self-help, and community groups and agencies. Third, the framework includes access to the basic resources that are needed to promote a desirable quality of life, including housing, income, work, and education. Fourth, the framework asserts that while medical science and social science are valuable ways to understand mental illness, they are not the only sources of knowledge. Experiential knowledge and the knowledge of lay persons are also valuable and need to be incorporated into mental health policy and programs. (253-54)

It is important not to lose sight of the reality that some service consumers are unable to participate in the kind of service model articulated here; and while consulting the input of

family members and other advocates is useful, these perspectives are not the same as accessing the first person experience of people with the most to gain by an advocacy campaign. All constituents have their own vested interest in whatever policy or program decisions are made, which will influence how and for what they advocate. It takes a considerable commitment by all participants to make collaborative planning processes work, and there is often not enough ‘buy in’ to sustain such initiatives over the long term.

Policy consultation with people with disabilities, in particular, has a history of political opportunism and tokenism. While active constituent participation in planning should contribute to program efficiencies by addressing service overlaps as well as gaps, the primary objective is the empowerment of the constituents affected by policy decisions. Unfortunately, Beresford and Croft have found that

[s]ocial work academics and practitioners may be prepared to concede service users’ knowledge and expertise in their own oppression as, for example, disabled people; and indeed to both call upon and rely upon that knowledge... However, they seem reluctant to concede service users’ expertise in the domain of anti-oppressive practice itself, preferring generally instead to see this as a developing academic discipline or specialism. (301)

Friere says that this kind of practice approach ends up oppressing both parties in the empowerment effort. For him, “[t]he solution is not to ‘integrate’ them into the structure of oppression, but to transform that structure so that they can become ‘beings for themselves’” (74). Systemic transformation is a difficult ideal for many social workers to work for, as it tends to set them in opposition to the institutions that employ them.

However, to the extent that social workers are able and inclined to work for the best interests of their clients, even to the extent of subverting existing institutional policy that

is experienced as oppressive or discriminatory, they are endorsing a structural or radical approach to policy planning.

Radical policy planning incorporates two distinct routes to social change. Both are grounded in the philosophical belief that “class structure and economic relations are perceived to be at the heart of problem definition. Planned change is generated through social movement, confrontations, alliances, and struggles” (Rothman & Zald 139). The most extreme radical theorists believe that the current social welfare system cannot be transformed from within and, as a result, they promote revolutionary means to overthrow institutional authority by society’s oppressed. Here, insurrection is assumed to be necessary in order to achieve the desired structural reform.

The other approach to radical planning borrows from advocacy and transactive philosophies to realize systemic transformation by working from within the existing political, economic and social welfare institutions. At the same time however, institutional systems aspire to maintain homeostasis and Canada has no real legacy of radical social change. For example, André Picard reported on a candle-lit vigil at Queen’s Park that was held to acknowledge the official closing of Ontario’s remaining institutions for people with intellectual disabilities, in 2009. In his article, he notes that it was 1971 when the Williston report first called on the Provincial government to look for alternatives to the ““large multipurpose residential hospitals”” (L4) that for more than a century had been the social policy response to mental disability in Ontario. Realizing this policy objective was the result of incremental policy adjustments over a very long period of time.



All social planning refers to that aspect of the policy process where needs are identified or, ideally, anticipated and proposes appropriate legislative intervention to address those needs. Hudson concludes that

[m]ost planners would admit that their craft is one of art as well as science. Most are uncomfortable, however, with depicting the future in the full richness of subjective color and detail which they know gives meaning to the present... planners are uncomfortable with the literary method, which may be a valid and accurate means of discussing social problems and solutions, but lacks the reliability and objectivity found in the more familiar tools of social science. (394)

The art of planning is practised from the United Nations on down to grassroots social action campaigns. Hudson's SITAR model contrasts the strengths and limitations of different theoretical approaches to planning that might help to contextualize how disability policy is conceived, and sometimes informed or challenged by the life experiences of people most directly affected by these systems of programs, services and regulations.

### **Policy Narratives and Case Studies**

Policy narratives may explain the ways that policy plays out in people's lives, thereby justifying certain policy choices and rationalizing outcomes when planning objectives are not realized. Couser observes that

[t]he interaction between narrative—cultural or personal—and law is multi-dimensional and multi-directional... Disability narratives—long or short, written or oral, formal or informal, individual or communal—may first stimulate legislation by highlighting areas in which protection from discrimination is lacking; those laws

in turn evoke narratives of their violation. Personal narrative may call for legislation, which in turn may call forth personal narrative. (2007, 82)

Couser's argument suggests a symbiotic relationship between law and narrative that policy makers might wish to explore in order to better plan for and predict the outcomes of policy interventions.

As evaluation tools, case studies are valuable sources of information with respect to demonstrating how policies shape the storyline of a person's life (Di Terlizzi 501; Flyvbjerg 66-78). Bent Flyvbjerg points out that the case study method is as important as it is enduring. He observes that every time Plato asked for universals, he was given case studies. He also quotes Donald Campbell, who says that "[s]ometimes we simply have to keep our eyes open and look carefully at individual cases—not in the hope of proving anything, but rather in the hope of learning something" (73). Social welfare planning cannot account for every contingency, and those invested with the responsibility for the administration of services are generally far removed from the places where policy is enacted at a personal level. Case studies that portray and comment upon individual experiences of human struggle or personal triumph invest policy discourses with meaning and relevance, and they shed light on the strengths and limitations of a policy narrative. This section provides an overview of dominant policy narratives that contextualize the institutional cycle in Ontario, and illustrates the role case studies play in critiquing those narratives.

Policy narratives may be constructed to predict social responses to human need in relation to issues that may affect the economic, environmental, health or social welfare of individuals and communities. For the policy analyst, policy narratives "can be defined as those stories—scenarios and arguments—that are taken by one or more parties to the

controversy as underwriting (that is, establishing or certifying) and stabilizing (that is, fixing or making steady) the assumptions for policymaking in the face of the issue's uncertainty, complexity or polarization" (Roe 3). Although structurally they will often follow prescribed protocols, they may also incorporate literary conventions to illustrate policy objectives and outcomes. Yanow explains that

[a]lthough metaphors may appear to be merely descriptive, outside the world of literature—in organizational and policy practices—they often acquire a prescriptive aspect. Metaphors no longer only present new insights into the situations they describe: they also suggest possible action in response to those situations.

Metaphors may express some prior, unarticulated understanding of the situations. That is, metaphors can be both models *of* a situation and models *for* it. (2000, 43; emphasis in original)

The values that generate a particular policy narrative are implicit in the way the social welfare issue is framed in terms of the constituents and the social context, or the characters and setting, concerned. For example, when a policy of institutionalization for people with mental disabilities was endorsed it promoted a narrative of care and cure. The subsequent policy narrative of de-institutionalization has incorporated metaphors of choice and inclusion.

In Ontario, policy narratives around disability can be seen to have come full circle, since May 11, 1839 when "the House of Assembly passed: 'An Act to authorize the erection of an Asylum within this Province for the reception of Insane and Lunatic persons'" (Simmons 1990, 3). This narrative told a story of people who needed to be institutionalized for their recovery; to protect them from themselves or unscrupulous people who would exploit and take advantage of them.

Hand in hand with that storyline went another dominant narrative that described how the mentally infirm needed to be segregated from the general public to prevent the spread of idiocy propagated by “feeble-minded” women who were represented as deviant and oversexed (Simmons 1982, 69-70; Reaume 31). Regardless of the reasons for political and community support for institutionalization, today its effect is interpreted by many disability advocates as having denied a substantial population a voice and visibility (Couser 2007, 72) in society.

Yanow explains how the study of built spaces can inform interpretive policy analysis. She says that “settings of policy and agency acts may communicate policy meanings other than, in addition to, or even contradicting those named in the policies themselves” (62). Descriptions of facilities for people with mental disabilities that use terms like “fortress” or “prison” (Sacks 1990, 25; Scull 49) imply social attitudes of fear and antipathy toward people living outside the cognitive or psychiatric norm. At the same time, Reaume also notes that while the “asylum itself was viewed with genuine fear and loathing by some... for others who felt they had nowhere else to turn it was perceived as a last refuge” (24). This is because in a pre-social welfare state, the institution or asylum provided refuge to people who were poor and too sick to support themselves, as well as abused or deserted wives and the elderly (Reaume 20).

The slow change of social attitudes regarding the place of mental disability in society speaks to how a dominant policy narrative, once it captures a society’s imagination, is hard to counteract. This is especially true when subjects of the dominant narrative have impairments that limit or preclude the ability to generate a viable counter-narrative. However, eventually the narrative did change as a result of a long period of advocacy led by parents of people with severe disabilities and other social reformers that

finally began to gain political momentum in the 1960s, culminating in a community living movement that took hold in the 1970s (Dunn 417; Marshall 7). The new dominant policy narrative endorsed a de-institutionalization storyline as more humane and appropriate to realizing personal growth and human rights entitlements. For example, Dunn praises what he perceives as a “paradigm shift from a medical and rehabilitation model to one based on consumer control, empowerment and self-help” (415); a perspective shared by many people who celebrate the closing of the remaining provincial institutional facilities in Orillia, Smiths Falls and Chatham-Kent, in 2009 (Picard L1, L4; Crawford, 27 Dec. 08, para. 2-3).

At the same time, those who oppose this narrative shift may be depicted as difficult, or in some way lacking in natural affections, even if those same people were once prevailed upon to relinquish custody of family members as the best option for meeting the disabled person’s needs. Reaume’s investigation of patient files from the Toronto Hospital for the Insane found that “some patients who escaped, sometimes to hundreds of miles from Toronto, returned on their own to live out their lives at the institution they decided was their home after decades of knowing no other environment” (71). This is consistent with sentiments expressed by some people in relation to the current de-institutionalization experience in Ontario. Some families have resisted the relocation of their relations who have lived most of their lives in an institutional facility that they recognize as their home. Alternative narratives— for instance, ones that address broken relationships between residents moved from their institutional homes to new community living arrangements (“Lifetime Friendships Lost” para. 1-14)— have rarely been published.

In this light the dominant narrative of the apparent success of de-institutionalization in Ontario needs to be critically considered. People living in the community may be less visible than when they reside in facilities that are required to meet standards of care, and are inspected regularly. Rose Galvin observes that the “rhetoric behind this move has been cloaked in philanthropic terms that are consistent with the aims of the independent living movement. In reality, however, this has proven to be a cost-cutting exercise” (47). Segregated services in institutions may be replaced by segregated services in the community (Dunn 415), as implied by Dr. Benjamin Goldberg’s belief that “it is possible to have ‘institutionalization’ in the community setting, and it is possible also to have ‘deinstitutionalization’ and the concept of normalization inside the institution” (In Marshall 41). Andrew Scull is also mindful of how similar rhetorical positions have been used over time to endorse opposing policy narratives advocating for or against institutionalization:

I would hope that those encountering our contemporary reformers and ideologues, who urge deinstitutionalization and praise the virtues of ‘community,’ may acquire a certain necessary skepticism from recalling how fervently their nineteenth-century counterparts once preached the gospel of retreat from the world and seclusion within the walls of the asylum. Similarly, both those who urge liberty for the lunatic and those who on the contrary complain of patients ‘dying with their rights on’ play out scripts with a long and checkered history. (7)

There is ample evidence that community integration is not the inevitable outcome of closing institutional facilities, as policy makers already consider the experiences of a growing number of people with mental illness and intellectual disabilities ‘falling through the cracks’, or the holes of Ontario’s existing social safety net.

Andrew Scull also cites evidence from both Canadian and American studies indicating that, when compared with people receiving community treatment, fewer people with mental health diagnoses who resided in hospital ““were incontinent, fewer took no part in bathing, more were able to bathe without help, fewer took no responsibility for their own grooming, more dressed without assistance, fewer failed to dress... and more had money available and were capable of making occasional purchases”” (Epstein & Simon in Scull 324). While this evidence must be dependent on the nature and degree of disability within a diverse population of people with disabilities, Scull also argues that there is no strong evidence that people being released from institutional facilities today are actually doing better, much less thriving in the wider community (315-316). Even if we agree that the lives of all members are enriched by living in truly integrated communities, it is irresponsible to ignore evidence that points to the vulnerability of mentally disabled people pursuing ‘independent living’:

The mother of a mentally disabled man says she talked to her son three times on the phone, unaware he was being held and tortured in a filthy attic apartment.

Though he sounded ‘tired,’ she didn’t know that her 22-year-old son, who has the mental capacity of a 12-15-year-old, was allegedly being beaten with pipes, forced to eat feces and burned over much of his body with a hair iron.

The man who cannot be identified due to a court order, was near death from toxic shock when police found him... (Morse, para 1-3).

This *Toronto Star* article goes on to report that the man had lived on his own with help from a social worker, and that his mother had given up all of her parental rights to get him the personal supports that he needed as a child (para. 10-11). Such media reports demonstrate the implications of policy narratives on individual lives, and are similar to

case studies to the extent that they contribute to a critical evaluation of policies, programs and services that influence these storylines.

At the locations where services are delivered, agency policy narratives may include reporting on program planning and evaluations. Program evaluations regularly expose significant discrepancies between stated policy objectives and actual outcomes. These occasions often provide rich data for interpretive analysis because “[b]y exploring the tensions or contradictions between intended and enacted meanings, the analyst can begin to assess whether the act is communicating some additional policy-relevant meaning” (Yanow 79). Case studies are often employed to demonstrate apparent disconnection between policy objectives and outcomes.

In fact, the case study method is utilized extensively in many health and social welfare agencies to meet a number of therapeutic and legislative ends. Di Terlizzi argues that case studies have the potential to demonstrate how “reports on [service] users’ views and life stories... shed new light on the diversity of individual outcomes” (501). She adds that the case study method is more appropriate than traditional program evaluation tools, as even contemporary interview techniques and emerging technologies cannot overcome challenges associated with “eliciting the views of people who have a communicative impairment” (502). This view echoes Sacks’ explanation for writing his case studies of his patients to depict life stories where severe neurological disease or disability is present. He is trying to bring the clinical interpretation closer together with the life experience; a practice that dates back to “that universal and prehistorical tradition by which patients have always told their stories to doctors” (Sacks 1998, viii). His commitment to a narrative method is motivated by his dissatisfaction with deficit-based case histories, observing that



[t]here is no ‘subject’ in a narrow case history; modern case histories allude to the subject in a cursory phrase... which could as well apply to a rat as a human being.

To restore the human subject at the centre—the suffering, afflicted, fighting, human subject—we must deepen a case history to a narrative or tale; only then do we have a ‘who’ as well as a ‘what’, a real person, a patient, in relation to disease—in relation to the physical. (1998, viii)

Oliver Sacks’ case study narratives have generated several books and substantial personal fame, as well as raising awareness about a population of people who were otherwise socially marginalized and ignored.

One of his most moving case studies is the story of Rebecca: a young woman with profound intellectual deficiency, offset by a strong spiritual capacity and a great appreciation for language and symbolism that could not be captured by diagnostic testing. He says that “my two visions of her—as idiot and as symbolist—met, collided and fused. She had done appallingly in the testing—which, in a sense, was designed, like all neurological and psychological testing, not merely to uncover, to bring out deficits, but to decompose her into functions and deficits” (1998, 180-181). In the construction of the case study, care needs to be taken to avoid emphasizing deficits, at the expense of considering strengths. The dramatic aspects of a case history are always recorded, but often what the clinician, care-giver or advocate needs to know is what a regular day looks like; the inevitably mundane aspects of day to day life are at least as important in getting to know an individual’s life story. Therefore, the author of the case study needs to constantly critically reflect upon the purpose of this construction and its implications in terms of therapeutic intervention for the client. In addition, the author’s professional obligations and status, and even political repercussions that may result from honest

documentation of a client or patient's life story also influence what information goes into a case study and how that information is represented.

Reaume's extensive study of client case files from the Toronto Hospital for the Insane speaks to a considerable range of depth in terms of case file content of patients between 1870 and 1940. Perhaps not surprisingly, he finds that the "lack of material in some files includes those of long-term patients who were among the most isolated inmates who had no outsiders inquiring about them" (5). Incomplete or deficit-based case studies are often the outcome of uninspired advocacy, and counter-productive intervention planning. Sacks (1998) also marvels about the lack of investigation and the brevity of data that often comprise the substance of contemporary case studies. In investigating one patient's rich and complicated life history he notes that he started with a very thin file: "This, then, was the tale I received, or, rather, put together from his chart or charts, documents so remarkable for what they lacked as for what they contained" (221-222). Case studies are regularly found to be lacking in terms of the depth of relevant information, as well as the range of sources that contribute to a cohesive and comprehensive client narrative.

Michele De Terlizzi expands further upon the implications of incomplete and deficit-based client histories that result in externally constructed life stories that are only partial, at best. More unfortunately, they often contribute to a distorted, unfavourable perception of the individual. At the same time, workers and caseloads change within agencies on a regular basis and a client case history may actually generate the first impression a worker has of the individual. Di Terlizzi's case study of Sue, a woman who had lived most of her life in a series of long-term care facilities, demonstrates the kind of difficult investigative work that needs to be undertaken in order to re-construct a life

history from the fragmented and often contradictory evidence in a case file. The researcher's indignation at the long-term lack of insight into Sue's life is apparent:

A scrutiny of the Special Care unit reviews and Ward 66 records contradict the statements relating to Sue's past achievements. It seems that the people who produced this report did not inspect Sue's hospital file and if they did so, it appears that they chose to dismiss their content. Another possible explanation could be that their assessment of Sue's potential was based on what they observed at the time. One of the regrettable features is the fact that the opinion 'nothing has been achieved in the past 24 years' was used to support predictions such as 'we could contain her only for a few months; I do not think with our staffing levels we could do better than this'. These people did not know Sue... . (510)

Clients often receive services from a number of agencies and their case histories follow them. A file that is already disproportionately focused on deficits becomes fragmented over time as the file is passed from different agencies and information is lost or disconnected from the contexts that gave it meaning.

Social work has a rich casework tradition of its own, where client histories are gathered in order to determine and justify the intervention taken to address client concerns. Beresford and Croft point out how client

experience and knowledges, reconstructed in the form of case notes, material and studies, have traditionally been used to legitimate, rationalize and promote social work. Originally when social work was mainly a charitable activity, they served a primary purpose in social work in both allocating and gaining money, and were used both in client assessment and organizational fund raising. When social work also became a statutory activity, they were employed more systematically as a data

source for management, research and theory building. It is important to remember, however, that this was service users' experience and knowledges as judged, interpreted and understood by social work and its agents. (300)

Because social workers are preoccupied with identifying and fixing problems, it is not surprising that the nature of personal dysfunction is the focus of most case note records. In many cases, organizational policy or legislative protocols determine the content of case histories and even how they are constructed.

Considering all that is not known about life stories that can only be narrated from the outside, it is prudent to avoid making unqualified assumptions about the feelings or needs of nonverbal people with mental disability diagnoses. It is at least possible that many of them are capable of composing something resembling that internal narrative that Bruner identifies as being so vital to the construction of selfhood, even if it cannot be expressed in language that others can easily understand. Referring again to Sacks' case study of Rebecca, he muses about the ways that this young woman with profound disabilities understands herself and her world: "[i]s it possible, I wondered, that this being before me—at once a charming girl, and a moron, a cognitive mishap—can *use* a narrative (or dramatic) mode to compose and integrate a coherent world, in place of a schematic mode, which, in her, is so defective that it simply doesn't work?" (1998, 181; emphasis in original). Through observation and direct engagement Sacks decides that Rebecca is "complete and intact as 'narrative' being" (181). For him, this means that she could present herself in a way that could be communicated as a narrative: a story with a purpose and a plot "and this is something very important to know, for it allowed one to see her, and her potential, in a quite different fashion from that imposed by the schematic mode" (1998, 182). Again, it is apparent that it is the personal story that contextualizes

disability, that gives meaning to the scientific diagnosis of different kinds of impairment, as well as the policy responses and planning initiatives designed to accommodate it.

As client files are typically fragmented and deficit-based, literary narrative can possibly provide vital context in trying to fill information gaps. Patrick McDonagh observes that “[l]iterary texts are useful historical documents because these often foreground how learning disabilities worked symbolically in a social context and enable us to examine the ideological forces shaping notions of disability” (2000, 49). Literary narratives, together with a range of informed perspectives, including insights from family members, friends and frontline workers can be incorporated into the client history, even if they contradict the prevailing expertise or the dominant narrative. This kind of research can help to fill in gaps in the life story communicated by people with severe mental disabilities, and diminish the effects of professional and cultural bias that the writer inevitably brings to the construction of the narrative.

Case histories contribute to the determination of client life plans, service eligibility, decisions about the ability to provide informed consent, or personal responsibility under the law. It is remarkable how much legal authority is ascribed to case histories constructed by social workers and other health and human services professionals, even when they are constructed with little or no input from the subject whose experience is being documented. Thus, there is enormous responsibility attached to writing a comprehensive and informed narrative, particularly when the subject of that narrative cannot directly challenge it. Jerome Bruner recognizes how a culture’s stories contribute to the content of our legislative systems:

Literature, exploiting the semblance of reality, looks to the possible, the figurative.

Law looks to the actual, the literal, the record of the past. Literature errs toward the

fantastic, law toward the banality of the habitual. But each is half a loaf, and in some covert way each knows it. Can we ever fit our discontents in the present to the writs and statutes of the past, as the law would have us do? Or, for that matter, can writers simply imagine the possible worlds they create without brooding over the constraints inherited from their past? How to wed memory and imagination? How does the comfort of predictability come to live with the excitement of possibility? The answer is, of course, that they only do so uneasily, even precariously. (2002, 61)

Traditionally policy planning honours the factual over the imaginative. What Bruner seems to be advancing is the idea that we need both to be able to access a rich reading of the past in order to imagine more effective and enriching policy options for the future.

## **CHAPTER 5- Methodology**

### **Research Problem**

Statistics Canada reports that 4.4 million Canadians reported having a disability in 2006 (cited in Prince 201); and most people with disabilities, including most people with mental disabilities, have the capacity to challenge representations of their life stories that are constructed within society's institutions and its cultural texts. Historically, all women and men with severe disabilities have experienced marginalization similar to other minority populations; however, their oppression is compounded when the ability to communicate their own life stories is impaired. Eva Feder Kittay points out that

[t]hose who speak do so in a language not recognized—and even demeaned—by those who speak in the language of the public sphere. Without a claim to cognitive parity, even those who can speak are not recognized as authors or agents in their own right. Those who cannot speak must depend on others to speak for them.

Those who can speak find that their voice is given no authority. Perhaps there is no more disabling disablement. (559)

When mental disability limits capacity for self-advocacy, the interests of these people are represented by family members, care givers, health and social work professionals. While there is a body of research that considers these perspectives, it is important to note that the representations of life narratives that are provided by workers, friends and family are interpretations that are inevitably filtered through the personal and professional values

and aspirations of caregivers and advocates. As a result, they cannot be assumed to be similar to the narratives that people would tell about their own lives.<sup>2</sup>

There are ethical as well as epistemological problems associated with representing individuals or groups who “are unable to change, contest or confirm how they are portrayed” (Iyer 127). Whether they work in direct practice with individuals, administration, program or policy planning, social workers have a professional obligation to work for the best interests of their clients (Westhues 5-8). However, many of the theories that social workers rely upon in professional practice with individuals, in service planning, administration and policy development cannot be easily evaluated without input from clients, service consumers or those most directly affected by policies that social workers advocate, implement and analyze. When the client has a communicative impairment that compromises or precludes the ability to express their interests through a narrative that is understood as coherent and reliable, social workers need to look beyond traditional, evidence-based practice models that cannot adequately address the unique combinations of experience, strengths, impairments and resources that contribute to an individual’s life story.

## **Historical Context**

Ontario has just completed what may be referred to as an ‘institutional cycle’, beginning with an Establishment phase in 1839 when legislation authorizing the establishment of the Province’s first Provincial Lunatic Asylum was passed (Figure 3). A

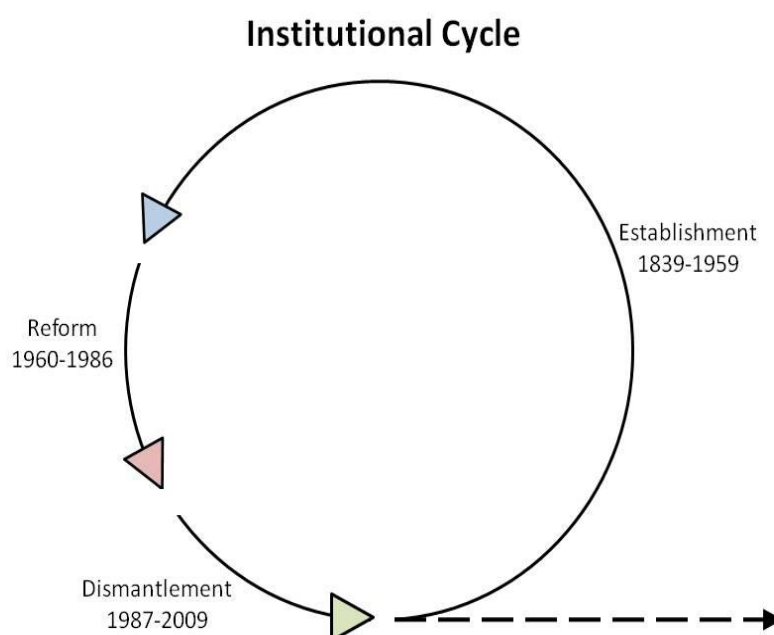
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<sup>2</sup> G. Thomas Couser (2002) invites the critical reader of disability life narratives to consider “a number of instructive questions: What sorts of relationships do memoir writers have to their disabled subjects, and how do these relationships inflect their narratives? To what extent do memoir writers mimic the ethnographic scenario in which the story of the other is written by a professional expert? What ethical questions arise when disability is narrated by a close relative or friend that do not arise in autobiography...?” (113)



subsequent period of Reform began in the 1960s, culminating with a pledge, in 1987, to close all Provincial long-term care hospitals for mentally disabled people over the next twenty-five years. From this point, Ontario entered a Dismantlement phase that concluded in spring 2009 when the three remaining long-term care facilities were finally closed.

**Figure 3**



### Theoretical Postulates

The research being proposed is grounded in the following theoretical assumptions:

1. Disability is a social or cultural construction that is unstable and changes over time, and across disciplinary perspectives.
2. Policy and literary discourses are cultural texts that contribute to the construction of our definition of disability.

3. Current social work theory does not adequately address how to work effectively for people who cannot speak for themselves.
4. Social workers have a professional obligation to work for the best interests of the client at individual, organizational and legislative levels of intervention.
5. Literary narrative is a legitimate resource to utilize for addressing social policy problems.

### **Purpose**

The purpose of this research is to undertake an interdisciplinary analysis of literary and policy discourses in order to better inform policy planning and service delivery for people with severe mental disabilities. It builds upon Michael Ignatieff's suggestion that the language of human rights does not adequately address the complexity of human need: "When we talk about needs we mean something more than just the basic necessities of human survival. We also use the word to describe what a person needs in order to live to their full potential. What we need in order to survive, and what we need in order to flourish are two different things" (10). He concludes that a language of human need cannot come from political discourse alone. Instead, he notes that "[i]t was in literature and painting rather than in political language that the possibilities of urban belonging were first given adequate images" (140); and further, that "[i]t is the painters and writers, not the politicians or the social scientists, who have been able to find a language for the joy of modern life" (141). Such a position speaks to the creative potential of a dialogue between policy and literary discourses to enrich a language of needs that may inform the efforts of social workers engaged in representing the interests of people who can not effectively advocate for themselves.

Consistencies or contradictions within or between different literary and policy texts may suggest corresponding agreement or disconnect between professional and cultural/social understandings of people with mental disabilities and their life experiences. In addition, this analysis may suggest possible correlations between dominant narrative themes and policy responses relevant to people with disabilities that have occurred before and might be predictable again.

Specifically, the research is designed to answer the following research questions:

1. What can be learned through a comparative examination of how mental disability is represented in literary and social policy discourses over the course of Ontario's Institutional Cycle?
2. How may an interdisciplinary analysis of literary and policy discourses inform policy planning and the provision of services for people with mental disabilities in Ontario?

## **Procedure**

The proposed research questions may be answered through a process of interpretive discourse analysis, which lends itself well to interdisciplinary knowledge generation. As the preceding overview of dominant literary, disability and policy approaches demonstrates, an interpretive discourse analysis entails “consideration of several alternative ways of conceptualizing the discursive domain under analysis” (Burman, sec 4 para 1). Discourse analysis is also well suited to a text-based study where “text *is the data* and the approach is therefore not about exploring ‘the’ content or meaning of the text. Rather, it is about explaining how certain things came to be said or done” (Cheek 147, emphasis in original). Discourse analysis contributes to generative

theory, which Goldstein describes as “pliable, inductive, open-ended, and therefore responsive to new information” (39). A generative or inductive approach to knowledge gathering is appropriate when the aim of the research is to find new sources of knowledge, rather than testing an existing sample.

Using a reflexive approach that entails reading and interpretation as processes that occur together, throughout the analysis, themes or patterns emerge through reading and re-reading the selected discourses. The data collected will consist of extracts from the selected literary and policy texts that demonstrate how disability is constructed in these discourses, within and between identified phases (Establishment, Reform, Dismantlement) of the institutional cycle. It is anticipated that themes generated by interpretive analysis of the data will identify dominant cultural assumptions about what is disability, as well as the experience, aspirations and potential of people with severe mental disabilities. Particular interest will be paid to points of transition in the Institutional Cycle to identify any corresponding shifts in dominant narratives about disability. Any rhetorical patterns, debates or contradictions between the stories and policies will be noted and their implications considered.

## **Rationale**

Goldstein explains how the humanities inform understanding of social welfare issues by suggesting that the “humanities do not profess to offer answers; rather, they encourage the kind of disciplined questioning and reflection that are fundamental to what effective [social work] practice may be. Not to be overlooked, the humanities enable us to understand the life of the sciences we depend on” (41). Turning more specifically to literature, several writers have theorized about its contribution to our understanding of

social welfare problems (Bruner 2002, 13-14, 194; Cohen 73; Iyer 127; Mar & Oatley 173, 180; Margolis & Shapiro 18; McDonagh, 2000, 49; Nussbaum 5-6; Peckham 227-228).

Novels have been identified as the most appropriate literary genre for answering the research questions because “[n]ovels... do not merely reflect the ideologies of their times. They also contribute, performatively, to the creation of those ideologies” (Miller 167). Furthermore, advances in mass production technology and growing literacy rates, as the product of an emerging public education system, were contributing factors that resulted in the rapid proliferation of the novel (Davis, 1998, 318) at the same time that political impetus to formalize institutional policy for people with mental disabilities was being established.

Franco Moretti has tracked literary publication trends in England from 1700-1850 and finds that the number of novels published in England rises sharply in 1840 (7), corresponding with the establishment of the Institutional Cycle. While this is not sufficient evidence to claim a direct correlation between the novel and emerging policy discourses about mental disability, it does affirm the merit in considering novels and policy together as relevant cultural texts associated with mental disability.

Martha Nussbaum (1995) writes specifically about the unique contribution that narrative literature, especially the novel, offers people who have the authority to influence policy change:

The novel is a living form and in fact still the central morally serious yet popularly engaging fictional form in our culture... [I]f we are going to speak about contemporary public life, and the ways in which concrete circumstances shape human emotions and aspirations, it seems wise to focus on a genre that is still

productive, and in which concrete circumstances that are relevant to our deliberations may be depicted. (6-7)

Novels are the most accessible narrative genre that both depicts and sometimes challenges dominant social, political and professional constructions of disability. This is the rationale for selecting novels as the most representative cultural discourse for representing life stories of people who are the subject of disability policy across the Institutional Cycle.

### **Themes for Analysis**

Regarding the data sample selected to answer the research questions, the following themes have been identified as fundamental to addressing the research questions:

**How Their Stories are Told-** The research problem is concerned with how social workers construct the life stories of people with limited or no capacity to speak for themselves. Therefore, it will be instructive to look to novels for insight into how disabled characters' stories are told. Narrative technique and point of view indicate who speaks for the disabled individual. Do people communicate their own stories in literary fictions? If so, how? In policy and in story it is important to consider who speaks for people with mental disabilities, as an indication of the value given the testimony of this population at different phases of the Institutional Cycle.

**The Role of the Family-** The relationship between people with mental disabilities and their families is central to the stories and policy that depict how people with mental disabilities should live, and who should support them. In all phases of the

Cycle the representation of family roles and relations draws attention to problematic assumptions in planning, administration and service delivery.

**Community Roles/Responsibility/Inclusion-** The perceived relationship between people with mental disabilities and their respective communities determines the storylines given to them in cultural texts, including novels, and the nature of services and supports defined in policy. When planning objectives do not realistically represent people's needs or community capacity then personal and policy outcomes are compromised.

**Perceptions of the Institution-** The role of institution may be influenced by family and community roles, and will be examined in each phase of the Cycle. This research understands institution as a long-term custodial care facility for people perceived to be mentally disabled. In addition, schools, hospitals and other facilities may also be relevant institutions for analysis where they function as an asylum, or as a training facility for people who have impairments that pose barriers to inclusion in the community. In some cases these impairments are the result of family dysfunction or structural discrimination that either contribute to or exacerbate mental disability.

### **Description of Sample**

In each phase of the Cycle three novels will be analysed, together with significant policy texts or legislation. There is much critical debate surrounding what constitutes social policy (Westhues 6). It "is a term replete with emotional content but lacking in agreed-upon meaning" (Lightman 37). In undertaking an interpretive policy analysis, Dvora Yanow argues that "[w]hereas traditional approaches to policy analysis focus on policies as exclusively instrumental and goal-oriented, interpretive approaches add the

expressive dimension of human policy-making action, demonstrating and enacting for a variety of audiences, near and far, what a polity finds meaningful” (88). Given the lack of consensus about what constitutes policy, an interpretive policy analysis should optimally consider a diverse selection of policy texts. Therefore, this study considers major legislative acts that have defined the parameters of formal policy related to people with mental disabilities. In addition, relevant policy planning and consultation documents, program evaluations, and critical commentary by researchers, practitioners, and in the public media, represent the range of disability policy discourse selected for analysis.

Given that the identified Cycle addresses a policy context specific to Ontario, all of the policy research, reporting, planning documents and legislation considered pertains to that jurisdiction. Policy sources have been selected on the basis of their historical significance and their contribution to moving the Institutional Cycle from one phase to the next.

The data sample is clustered around the formal commencement of the Cycle that occurred with passage of legislation to open Ontario’s first lunatic asylum, and near subsequent points of transition between phases. The selection of relevant novels aspires to diversity by considering literary sources that have influenced the cultural construction of disability by virtue of their popularity, critical acclaim, or in terms of innovative ways that they represent or challenge dominant constructions of mental disability. The literary sample includes both male and female characters who embody a range of impairments that are diagnosed as mental illness or mental disability. The sample also reflects the influence that British and, later, American cultures have had on policy responses to disability in Canada, specifically Ontario.



**Table 3- Establishment Phase**

Year	Policy Texts and Events	Narrative
1839	“An Act to authorize the erection of an asylum within this Province for the Reception of Insane and Lunatic Persons”	
1841	First Provincial Lunatic Asylum opens in Ontario	Dickens, <i>Barnaby Rudge</i>
1847		Brontë, <i>Jane Eyre</i>
1850	999 Queen Street West opens	
1855		Gaskell, <i>Half a Life-Time Ago</i>
1866	An Act Respecting Municipal Institutions of Upper Canada	
1876	Orillia Lunatic Asylum opens	
1897	Russell, “The Relation of Insanity to the State”	
1900	An Act Respecting Lunatics	

The Establishment phase covers over 120 years of expansion of the institutional system in Ontario, and is disproportionately long in comparison with subsequent Reform and Dismantlement phases. In order to keep the scope of the present research within manageable parameters a number of factors were considered. First, literary narratives for the Establishment phase sample were selected on the basis of their proximity to the commencement of the Institutional Cycle, in 1839, in order to obtain a sample most representative of cultural attitudes at the time when it was deemed necessary to introduce a formal policy of institutionalization.

In terms of policy analysis, the potential sample is much smaller than in subsequent cycles of the Institutional Cycle. In addition to the 1839 Act to authorize the establishment of the Province’s first lunatic asylum, the 1866 Act Respecting Municipal Institutions of Upper Canada addresses the status of idiots and their management in society.

Dr. Russell's (1897) speech to the British Medical Association is included in the sample, as he speaks specifically to contemporary theories of insanity and the government's role in the care and control of the "defective classes"(3), from his perspective as Superintendent of the Asylum for the Insane, in Hamilton Ontario.

An Act Respecting Lunacy is also included to explicate the distinction between mental illness (lunacy) and mental disability (idiocy) in law.

Analysis of the policy context for the Establishment phase is substantially informed by secondary analysis of research produced by Harvey G. Simmons (1982, 1990), Geoffrey Reaume (2000), and others who have undertaken comprehensive historical analysis on the lives of people residing in Ontario institutions.

Because Upper Canada was a British colony and its social policy was most heavily influenced by British law and cultural traditions, the sample for this phase is comprised of English novels. In addition, the potential sample was further refined to include only those narratives that remain in print in order to better ensure selection of stories that have enduring popularity and relevance to contemporary readers. These criteria ultimately limit the potential sample to a relatively small selection of English novels that depict characters with mental disabilities.

It is rare for a mentally disabled character to be the eponymous hero of a novel. Therefore, Charles Dickens' *Barnaby Rudge* (1841) is significant for placing the idiot character in the centre of the story's action. Even though it is not one of Dickens' more successful novels, by any other writer's standard it garnered a substantial audience.

Charlotte Brontë's novel, *Jane Eyre* (1847) was an immediate success, upon its original publication (Davies ix, xi), and has remained tremendously popular since that time. In addition, the character of Bertha Rochester marks the establishment of a

narrative archetype—the ‘madwoman in the attic’-- that is re-visited in selections from subsequent phases of the Cycle.

Elizabeth Gaskell’s novella, *Half a Life-Time Ago* (1855), is included in this set because Gaskell’s work was very popular. She was a regular contributor to Dickens’ weekly magazine, *Household Words*, which was where *Half a Life-Time Ago* was first circulated (Easson ix). Also, Willie Dixon contributes to the diversity of the sample in that his disability is acquired as a result of illness, and the story addresses many of the issues that have been central to the debate around a policy of institutionalization.

Mental disability has historically been constructed as either lunacy or idiocy. The literary sample for the Establishment phase offers different manifestations of mental disability: Dickens’ *Barnaby Rudge*, is born an idiot; Brontë’s *Bertha Rochester* is a lunatic; and Gaskell’s *Willie Dixon* whose mental incapacitation is acquired as a result of illness.

**Table 4- Reform Phase**

Year	Policy Texts and Events	Narrative
1960	Berton, “What’s Wrong at Orillia...”, <i>Toronto Star</i>	
1962		Kesey, <i>One Flew Over the Cuckoo’s Nest</i>
1966		Rhys, <i>Wide Sargasso Sea</i>
1971	‘Williston Report’	
1973	‘Welch Report’	
1974	Developmental Services Act	
1980		Krantz, <i>Princess Daisy</i>
1982	Clark v. Clark	

Relevant policy texts selected for analysis include Pierre Berton’s *Toronto Star* column, “What’s Wrong at Orillia: Out of Sight—Out of Mind” (6 Jan 1960) because it brought the institutional crisis to wider public attention. Public reaction to this column

generated a political response that contributed a growing movement to reform the institutional system in Ontario.

In 1971, Walter Williston was commissioned by the Ontario Minister of Health to investigate the circumstances surrounding the deaths of two individuals who were under the guardianship of the Rideau Regional Hospital, at Smiths Falls. His report, "Present Arrangements for the Care and Supervision of Mentally Retarded Persons in Ontario," is a comprehensive analysis of the institutional system serving mentally retarded persons in the Province. The 'Williston Report' findings greatly influenced subsequent planning for people with mental disabilities and accelerated a shift toward de-institutionalization and community living.

Walter Welch's report, "Community Living for the Mentally Retarded in Ontario: A New Policy Focus" (1973) was the Ontario Government's official response to Williston's findings. In his capacity as Provincial Secretary for Social Development, Welch outlined the needs of people with mental disabilities and the limitations of the current system. His report outlines a plan for downsizing the institutional sector that considers a range of planning options, and a corresponding analysis of costs and benefits.

The Developmental Services Act (1974) is an important piece of legislation that was introduced to respond to the transfer of responsibility of people with developmental disabilities from the Ministry of Health to the Ministry of Community and Social Services. It also establishes the regulations governing community living organizations that supported people being diverted or released from provincial institutions.

Judge John Matheson's decision in the case of *Clark v. Clark* is included because it offers another perspective on the role of families in determining the life plans of people with mental disabilities, as the Dismantlement phase of the Cycle was approaching. It is

considered a ground breaking case for many disability activists (Roehrer Institute 1996) because it endorsed the right of a person with substantial mental and communication disabilities to challenge familial authority, and exercise the choice to leave the institution.

These policies are considered beside novels that portray characters with mental disabilities, their relationship to the institution, and wider society. Ken Kesey's *One Flew Over the Cuckoo's Nest* (1962) was a best-selling novel in North America. *Time* magazine includes it on its list of 100 best English language novels of all time (Grossman & Lacayo). Set in a psychiatric ward for long-term patients, the story represents people with mental disabilities as casualties of a dysfunctional society. Stereotypes of mental disability are interrogated together with cultural assumptions pertaining to race and gender.

Jean Rhys' novel, *Wide Sargasso Sea* (1966), is important for the way that it "writes back" (Jenkins viii) to cultural assumptions that the author perceives in Brontë's creation of Bertha Rochester. Rhys critically analyses the 'madwoman in the attic' as a casualty of cultural tradition that oppresses women in society. The novel explores how the cultural and legal subjugation of women are at least contributing factors to Bertha Rochester's madness.

Both Kesey's and Rhys' novels were published within a few years of the beginning of the Reform period of the Institutional Cycle. Judith Krantz's novel, *Princess Daisy*, was published closer to the transition to the Dismantlement phase of the Cycle, and is included in the Reform sample because it was one of the best-selling novels of 1980. Krantz portrays a world that equates beauty and virtue, and presents an uncritical portrayal of the institution as the an asylum for a mentally disabled character who presumably does not belong in the wider world.

**Table 5- Dismantlement Phase**

<b>Year</b>	<b>Policy Texts and Events</b>	<b>Narrative</b>
1987	“Challenges and Opportunities” report	
1995		Findley, <i>The Piano Man’s Daughter</i>
2004		Haddon, <i>The Curious Incident of the Dog in the Night-Time</i>
2005	Marin (Ombudsman Ontario), “‘Between a Rock and a Hard Place’...”	Edwards, <i>The Memory Keeper’s Daughter</i>
2006	Parsons, “Consultations Regarding the Transformation of Developmental Services”	
	“Opportunities and Action” report	
	Dingwall, Kemp & Fowke. “Creating a Good Life in Community: A Guide on Person-Directed Planning”	
	“Out of the Shadows at Last...” (Kirby Commission report)	
2008	Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act	

A substantial amount of policy discourse has been generated since the Government of Ontario’s “Challenges and Opportunities Initiative” (1987) formally declared the long-range objective of closing provincial institutions for people with mental disabilities.

In 2005, the Ombudsman of Ontario, André Marin, produced a report responding to complaints by Ontario parents who could not access intensive behavioural and residential supports that their severely disabled children required without relinquishing custody of these children to the Children’s Aid Society. Marin admonished the Ministry

of Children and Youth to address the problem of inadequate, or nonexistent government services necessary for families to support their children with severe mental disabilities.

In 2006, the Parliamentary Assistant (Disabilities) to the Minister of Community and Social Services, Ernie Parsons, produced his report on “Consultations Regarding the Transformation of Developmental Services”. This document reports on consultations with family members and service providers for people with developmental disabilities, and makes recommendations regarding the service priorities and planning for people with developmental disabilities in a post-institutional society.

Later that same year, the Government of Ontario released a planning document, the “Opportunities and Action” report, which proposed a new system for people with mental disabilities to access the services and supports required to meet their specific daily living needs. A corresponding planning guide (Dingwall, Kemp & Fowke, 2006) defines roles for service recipients, family members and community partners to realize personal planning goals.

The Standing Senate Committee on Social Affairs, Science and Technology released “Out of the Shadows at Last: Transforming Mental Health, Mental Illness and Addiction Services in Canada”, in 2006. Authored by Committee Chair, Michael J. L. Kirby, this comprehensive analysis of mental health services in Canada is commonly known as the ‘Kirby report’. It speaks to the community living experiences of people who are diagnosed with a chronic mental illness and are trying to maintain good mental health. Many of the issues of housing instability, inadequate personal supports, poverty and isolation speak to the same concerns highlighted by people diagnosed with developmental or intellectual disabilities.

The 2008, Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act was enacted to replace the 1974 Developmental Services Act. It defines a service structure for people with developmental disabilities in post-institutional Ontario. Some sections of the Act have not yet been proclaimed.

The literary sample that accompanies Dismantlement policy discourse includes novels set across in all of three phases of the Institutional Cycle. Timothy Findley's *The Piano Man's Daughter* (1995) is set in the Establishment period, beginning in 1889 and concluding in 1946. In addition to offering a retrospective representation of how one woman with a mental disability participated in family and community life this novel also offers a third perspective on the 'madwoman in the attic'. The novel was also selected because Findley is an internationally acclaimed writer (O'Malley & Potash, para. 2) who addresses mental disability in many of his novels with insight and sensitivity. As a Canadian writer, his novel contributes a distinctly Canadian perspective and offers historical insight about disability and mental health policy that is specific to Ontario in the first half of the twentieth century.

Mark Haddon's, *The Curious Incident of the Dog in the Night-time* (2004) is set in a suburb of contemporary London and was an international best-seller. The story is narrated in the first person, by the mentally disabled character, and this narrative anomaly contributes a new dimension to analysis of how people with mental disabilities may tell their own stories.

The majority of the action in Kim Edwards' novel, *The Memory-Keeper's Daughter* (2005), is set in the Reform phase of the Cycle, beginning in 1964 through 1985. In this novel the disabled individual is not an active character throughout most of the storyline. However, she is omnipresent and influences the storylines of the other



major characters in very significant ways. Like Haddon's book, Edwards' novel was both popular and critically acclaimed.

Collectively, the literary sample in this phase depicts characters with the most recognizable mental diagnoses in contemporary society: chronic mental illness, autism, and Down syndrome. The novels selected in the final phase of the cycle are representative of the three dominant cultural influences in terms of social policy in Ontario: A Canadian, a British and an American novel comprise the sample here. Finally, newspaper articles and nonfiction narrative also contribute to policy discourse.<sup>3</sup> Where pertinent, such texts will also be considered in the analysis.

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<sup>3</sup> Jutta Weldes' refers to "high" and "low" data sources to refer to peer-reviewed research and mainstream or popular media, respectively. He argues that both are essential for interrogating culturally constructed concepts (178-180).

## **CHAPTER 6- Analysis of Establishment Phase 1839-1959**

### **Introduction**

It is convenient to identify the beginning of the Institutional Cycle in Ontario at the date when the first legislation designed specifically to care for mentally disabled people was passed in Upper Canada, even though the 1839 Act to Authorise the Erection of an Asylum within this Province for the Reception of Insane and Lunatic Persons (Statutes of Upper Canada, Ch. XI) was a deliberate response to a social welfare issue that had already been long debated and responded to in a number of different ways.<sup>4</sup> Traditionally, people who were perceived as idiots, naturals or lunatics were cared for by extended family networks, and the community at large (McDonagh, 2008, 41). However, changes in social and economic organization displaced people who were not attached to the waged labour economy, and needed daily living care (Davis, 1997, 9-11; Simmons, 1982, 41-42).

Political pressure to develop an institutional response arose from a recognition that, as a formal social welfare system in Upper Canada began to emerge, people who could not contribute actively to the new economy found themselves on the margins (J. Russell 8): often living out of doors or taking up space in prisons, hospitals and poor houses. All of these factors contributed to the erection of the first Provincial Lunatic Asylum, which

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<sup>4</sup> To cite just two comprehensive historical treatments, Michel Foucault's (1965) *Madness and Civilization* traces political and cultural constructions and response to madness in Western Europe from the end of the Middle Ages. Patrick McDonagh's (2008) *Idiocy: A Cultural History* specifically traces the history of the construction of idiocy in (predominantly) English literature from the sixteenth century.

opened with 17 patients in 1841, [and] was originally situated in the county gaol on Toronto Street. There was not enough space, however, so branch facilities were set up in a house at the corner of Front and Bathurst Streets and in the east wing of the colonial legislative buildings. In January 1850 a new insane asylum located three miles west of downtown Toronto, at 999 Queen Street West, received its first patients. (Reaume 6)

The passage of this legislation thus marks the formal recognition of mentally disabled people as a distinct component of the population in Upper Canada (Ontario). The subsequent policy that has been built upon this initial Act provides a framework that determines the life opportunities of people who have been unable to articulate their own life narratives and aspirations.

Harvey Simmons traces the separate histories of the asylum systems for people who were designated as idiots (1982) or insane (1990), and finds what Geoffrey Reaume's later research reaffirms: that these distinct policy responses often overlap, as a result of the haphazard way that individuals were assigned to one system or another (Parsons 5).

Very early on the government of Upper Canada tried to ignore the mentally retarded people who were found in the first lunatic asylums established in the province. Nevertheless the authorities were forced to deal with them, initially by barring them from admittance to the lunatic asylums and later by providing special facilities for them along with others labelled as "chronically insane". This was policy by inaction, or inadvertence, for by establishing lunacy policy and deliberately trying to ignore mentally retarded people the authorities in Upper Canada nevertheless found themselves making policy regarding mentally retarded

people. Thus on occasion the term “policy” refers to government actions which indirectly affected the fate of mentally retarded people. (Simmons 1982, xiii)

Ontario’s first Idiot Asylum, originally the London Lunatic Asylum, opened in 1872 for the purpose of segregating the chronically insane from those that the lunatic asylum purported to cure.<sup>5</sup> The Province’s largest facility was devoted exclusively to the care of idiots, feeble-minded, mentally retarded, developmentally disabled opened at Orillia in 1876 (Government of Ontario, 2006, 5; Radford & Park 3).

At the time when an institutional policy was established the jurisdiction of Upper Canada was an English colony. As a result, Establishment era social welfare policy was heavily influenced by the English legislative system. Along with its political system, British literature also contributed significantly to the cultural fabric of Upper Canada, as the Canadian literary canon was barely in its infancy. As a result, the narratives that contributed to an emerging nation’s construction of disability were, at least at the beginning of this phase, also mostly English. Popular and enduring literary narratives published in and around the establishment of the first institutional policy for people with mental disabilities include, Charles Dickens’ *Barnaby Rudge* (1842); Charlotte Brontë’s, *Jane Eyre* (1847); and Elizabeth Gaskell’s novella, *Half A Life-time Ago* (1855). These narratives in some ways reflect and reinforce social assumptions inherent in the 1839 Act that marks the Establishment of the Institutional Cycle in Ontario and its long period of expansion.

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<sup>5</sup> Confusion around appropriate diagnosis and treatment of lunatics and idiots existed in all jurisdictions where the asylum system was evolving. In France, Pinel who pioneered the practice of moral therapy observed that “‘Ideots constitute the greatest number of patients at lunatic hospitals; and their pitiable condition, has in too many instances, originated in severity of treatment experienced at other places.... At Bicêtre idiocy constitutes one fourth of the whole number of patients,’ in large part, he claims, because the hospital is considered a repository for the untreatable” (In McDonagh, 2008, 58)

### **How Their Stories are Told**

Little scope is given for a person with mental disabilities to tell his or her own story in Establishment policy or literature. In the mid-nineteenth century, politicians and medical superintendents might consult other experts, but the experiences of frontline workers or family members were not considered, much less the opinions of the idiots or lunatics who were the subject of institutional policy. Whether or not the resulting policy was more effective, the administrative system that produced it was smaller, more stable and less dynamic than the political bureaucracies that have evolved over the course of subsequent phases in the Cycle. This is evident by the comparatively slender policy legacy generated at the beginning of the Establishment period, in contrast with subsequent policy phases that had more substantial bureaucracies dedicated to addressing contemporary issues in disability policy.

Contemporary disability scholars have attempted to compensate for the absence of first-person stories at the outset of the Institutional Cycle through ethnographic research. Geoffrey Reaume, for example, has researched the patient files at Ontario's largest and most famous asylum: the Toronto Hospital for the Insane, at 999 Queen Street West. His work makes an important contribution to our understanding of what institutional life was like for patients who resided there. Still, he admits that surviving records of first-person narratives are quite thin (5). This makes the Establishment novel a particularly important source for portraying dominant cultural constructions of disability that influenced and was influenced by policy assumptions at the time.

Dickens novel, *Barnaby Rudge*, was published in 1841, two years following the commencement of the Institutional Cycle in Ontario. It's a historical novel, set during the

Gordon Riots, which occurred in 1780 (Bowen xvi). The eponymous hero of the novel is an idiot, cared for by his devoted mother, but also by the wider community. Dickens establishes his primary characters in a small village where social ties are strong. There is an intimacy between the residents that fosters stronger relationships between Barnaby and the characters who contribute to his life narrative. Furthermore, despite his intellectual impairments, Barnaby is very capable of telling his own story. Even though he is not a consistent presence in a story with many characters and storylines, the reader ‘hears’ Barnaby’s voice as clearly as any of the other major characters in the novel, which is a rare occurrence in literature from this period (Bowen xxii).<sup>6</sup>

*Jane Eyre* is a retrospective narrative told in the first person by the title character of the novel. There is an intimacy created between the narrator and the reader that is contrived, in part, by the tendency for Jane to address the reader directly, particularly at major turning points in the story.<sup>7</sup> In contrast, Bertha Rochester is depicted mostly as a mysterious and sinister presence, rather than an actual person. The reader never has access to her thoughts, and only receives her story third hand, as it is Jane’s account of what Rochester tells her about his wife’s history. In fact, Jane is never actually present to hear Bertha say anything for herself. The only words ascribed to Bertha over the course of the novel’s action only further elucidate her depravity, as her brother attests that when Bertha attacked him with a knife and with her teeth, “‘she said she’d drain my heart’” (Brontë 246). Otherwise, the raving that Jane hears, and eventually witnesses, is inarticulate. Furthermore, Rochester’s version on his wife’s story cannot necessarily be

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<sup>6</sup> Earlier drafts of the novel were named for Gabriel Varden, who represents “solid middle-class citizenry” (McDonagh, 2008, 174) and is most directly responsible for bringing about the restitution of social order, and saving Barnaby from the gallows. Bowen believes that Dickens’ decision to name a novel “after someone as socially marginal and intellectually weak as Barnaby is a remarkable act of confidence in his own dramatic powers” (xxii).

<sup>7</sup> Perhaps most famously, “Reader, I married him”, at the beginning of the concluding chapter.

relied upon, as he is a man who feels duped into a marriage that he has regretted from the outset; and he is trying to defend his attempt to lure Jane into a bigamous union.

Like Dickens, Gaskell also sets her novella in a rural setting that emphasizes the intimacy of relationship between the characters. She also sets her story back in time. In *Half a Life-time Ago*, Willie Dixon's story is told retrospectively from the perspective of an omniscient third-person narrator fifty years after the action of the story takes place. There is almost a fairytale, 'once upon a time' feel to the story right from its opening lines: "Half a life-time ago, there lived in one of Westmoreland dales a single woman of the name of Susan Dixon" (Gaskell 3). The narrator then proceeds with a description of a rural past that is picturesque in its rustic simplicity and evocation of a way of life that reaches back generations.

Setting the idiot in an idyllic, pastoral backdrop was a well established literary convention by this time. Literary critics have linked Gaskell's novella with William Wordsworth's poem, "The Idiot Boy" (1798), published in his collection of *Lyrical Ballads* (Easson x). In addition, the maternal devotion that Wordsworth's Betty Foy has for her idiot boy is replicated in Susan Dixon's fond affection for her brother, Willie; and also in Mary Rudge's relationship with her son, Barnaby. The perspectives of these characters are crucial in the novels as they are called upon to speak and advocate for the mentally disabled individual, whereas Bertha Rochester's primary spokesperson is a man who loathes her and sees his mentally disabled wife as an obstacle to his happiness. Thus, the relationships between the idiot or lunatic to their families and community have a substantial influence in the ways that their stories are constructed, and determinations that are made about their care.

### **The Role of the Family**

Nineteenth-century English literature typically identifies mental disability as the personal misfortune or burden of the individual, regardless of how it is acquired. The community has no inherent responsibility to directly care for or protect the individual, although the passage of legislation to erect Upper Canada's first lunatic asylum included a provision to tax "each and every inhabitant householder... an additional rate of assessment of one-eighth of a penny in the pound" (XIII) to offset the cost of building and maintaining the lunatic asylum. Otherwise, care and control of the disabled individual was perceived at this time to be the exclusive responsibility of the family, and where the family was unable or unwilling to carry out that responsibility the individual was typically contained in a workhouse, jail or hospital if he or she was unable to work for a living. This section considers how novels and policy discussion hold family responsible for causing or exacerbating mental disability in the individual. At other times, however, the love of a good mother or devoted sibling is shown to be essential for maintaining the mentally disabled individual's personal security and place in the community. This caring labour is also represented as morally correct and personally rewarding for the caregiver.

The original legislation for the Provincial Lunatic Asylum held families responsible for the costs of maintaining patients (VII). However, given the high proportion of destitute lunatics who were maintained in the asylum at the expense of the State (VIII), many families simply abandoned their relatives in order to relieve themselves of responsibility for their maintenance. In his remarks to the British Medical Association (1897), the Superintendent of the Asylum for the Insane at Hamilton Ontario affirmed that there was "abundant evidence" that the public abused the privilege of



government funded care intended for those who have no other means of support (J. Russell, 7).

The role of the family in relation to people with mental disabilities is depicted in Establishment novels in a number of different ways. In some cases, the mental incapacity of the individual is portrayed as the devastating inheritance from parents who themselves are deranged, or behave immorally. At other times the presence of the disabled individual highlights the selflessness of family members who devote their lives to caring for the idiot. These novels speak to the personal toll that being the familial guardian of the disabled individual can take, but these caregivers also know the satisfaction of unconditional love from those who are so dependent upon them. Finally, the vulnerability of the disabled individual is conveyed in the ways that they are exploited and abused by those who reject their duty to provide care and protection.

In the latter half of the nineteenth and early twentieth century, lunacy is often linked with some kind of individual or degenerative moral failing that may be traced back through the parents, and perhaps further (McDonagh, 2008, 258-263). For instance, “*Barnaby Rudge* is very concerned with the nature of inheritance, in particular what we inherit from our parents” (Bowen xxvi). Barnaby is even physically marked by his father’s evil by the blood red birth mark on his wrist (Dickens 5).

On the other hand, Jane Eyre’s isolation contributes to inflaming her passionate nature to a point verging on madness. Orphaned, and under the care of her Aunt Reed, the widow of her mother’s brother, Jane is mercilessly abused by a family who does not want her. John Reed torments Jane with epithets that dehumanize her. He calls her a “bad animal” (Brontë 11), and when Jane retaliates against his assault she admits that “he had closed with a desperate thing” (Brontë 14). When the nursery maid comes to help

restrain Jane, she compares her to a “mad cat” (Brontë 15); and Jane recalls how she “looked doubtfully on my face, incredulous of my sanity” (Brontë 16). This episode occurs at the beginning of the novel, and the animal metaphors used to describe Jane in her distress anticipate the isolation and apparent distress of a similarly incarcerated Bertha Rochester at Thornfield.

When Jane is punished for defending herself against her cousin’s assault she is confined in the upstairs bedroom where her uncle died. Jane’s terrified imagination manifests a vision of a spirit that provokes a kind of fit where she admits that “[a]ll John Reed’s violent tyrannies, all his sisters’ proud indifference, all his mother’s aversion, all the servants’ partiality, turned up in my disturbed mind like a dark deposit in a turbid well” (Brontë 18). In this way, Brontë demonstrates how a child who is starved of affection and a sense of belonging is vulnerable to strange terrors that may disturb the mind.

Gaskell, on the other hand, de-emphasizes a hereditary explanation for madness in her story by stressing the sobriety and temperance of the Dixon lineage: “William Dixon and Margaret Dixon were rather superior people, of a character belonging—as far as I have seen—exclusively to the class of Westmoreland and Cumberland statesmen—just, independent, upright; not given to much speaking; kind-hearted, but not demonstrative; disliking change, and new ways, and new people; sensible and shrewd” (Gaskell 4-5). This description of the family’s lineage extends to the character of the community generally and explains Susan’s own characteristic reserve.

This does not mean, however, that the Dixon parents are not susceptible to poor judgment. Susan’s and Michael’s union had initially seemed an advantageous alliance to both families as a means of merging their farms and the assets that they generated: “Both

fathers and mothers cast a glance from time to time at Michael and Susan, who were thinking of nothing less than farm or dairy, but whose unspoken attachment was, in all ways, so suitable and natural a thing that each parent rejoiced over it, although with characteristic reserve it was never spoken of” (Gaskell 6). Even parents with good intentions for their children’s interests are shown to be fallible in their judgment, particularly when other interests, like the combination of assets and property influence perception.

Edward Rochester’s father and Bertha Mason’s parents, however, are blatantly deceitful in manipulating the disastrous match between their children. Rochester’s “avaricious and grasping” (Brontë 351) father arranged the match so that his second son would be wealthy without having to divide the family fortune. Having found an eligible candidate in the daughter of business partner, who would offer a dowry of thirty thousands pounds, Rochester explains how after college he was dispatched to Jamaica, ““...to espouse a bride already courted for me. My father said nothing about her money; but he told me Miss Mason was the boast of Spanish Town for her beauty; and this was no lie... a marriage was achieved almost before I knew where I was”” (Brontë 352). He admits that Bertha was also used as her family’s currency to secure a fortune, and explains that it was only after his wedding that he learned about the family’s history of madness “for they were silent on family secrets before. Bertha, like a dutiful child, copied her parent in both points” (Brontë 337); these points being madness and drunkenness.

The tradition of placing economic considerations above personal compatibility in marriage is one that Jane also, albeit reluctantly, endorses when she presumes that Rochester will propose marriage to Blanche Ingram. Watching them together, Jane

admits to herself: “I had thought him a man unlikely to be influenced by motives so commonplace in his choice of a wife; but the longer I considered the position, education, etc., of the parties, the less I felt justified in judging or blaming either him or Miss Ingram for acting in conformity to ideas and principles instilled in them, doubtless, from their childhood” (Brontë 217). It was considered natural for people to marry within their social class, to their economic advantage, and Jane’s acceptance of that social convention justifies, at least to some extent, the circumstances that facilitated Rochester’s existing marriage. Therefore, it seems unfair to make Bertha bear the brunt of responsibility for such an arrangement between herself and Rochester. Still, despite his self-recriminations for being the dupe of his own family’s ambitions, Rochester does not evince any compassion for his wife being placed in similar circumstances. In fact, as a woman she would have had even less ability to assert herself against a match that her family would have arranged for her interest and their own: a complexity that Jean Rhys explores in her re-construction of Bertha’s life-narrative in *Wide Sargasso Sea*.

Because Jane recognizes the supremacy of Bertha’s claim, as a wife, on the man she loves, she must sacrifice that love; but she ultimately gains new family relations and financial independence by choosing the right course. Similarly, Gaskell’s Susan ultimately gains by insisting on the moral course of action in honouring her deathbed pledge to her mother to care for her brother Willie who, following his illness, is subject to fits and requires “the same care taken of him that a little child of four years old requires” (Gaskell 24). When Susan refuses to concede to Michael’s demand that Willie be institutionalized upon their marriage “[t]he sacrifice she had made for this object only made it more precious to her” (Gaskell 37). Furthermore, the house-servant responds to the broken engagement by declaring that “[w]e’re rid of bad rubbish anyhow” (Gaskell

33). Peggy's assessment of the break-up as an act of good fortune proves correct, as Michael ultimately degenerates into a life of dissipation that leaves the wife that he does take and their children living in destitute circumstances. Willie's disability, therefore, may be read as his sister's salvation.

If Gaskell's story points to the family as the best asylum for the disabled individual, and Brontë depicts how dysfunctional families can also be the source of the malady, Dickens creates a character whose idiocy is caused by the moral depravity of the father, although he is saved by the goodness of the mother who loves the offspring of her disastrous union "better than she loved herself" (Dickens 208). Barnaby's idiocy, like the blood red birthmark on his wrist, is the legacy left by his father following as a result of the shock that his pregnant mother suffered upon seeing him after the murder he committed (Dickens 5).<sup>8</sup> Barnaby is born the day his father leaves the scene of his crime, and Mary Rudge subsequently devotes her life to his care. By the time Barnaby is grown she is

about forty—perhaps two or three years older—with a cheerful aspect, and a face that had once been pretty. It bore traces of affliction and care, but they were of an old date, and Time had smoothed them. Any one who had bestowed but a casual glance on Barnaby might have known that this was his mother, from the strong resemblance between them; but where in his face there was wildness and vacancy, in hers there was the patient composure of long effort and quiet resignation. (Dickens 49-50)

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<sup>8</sup> McDonagh (2008) points out that "as late as 1904, the American physician Martin Barr stresses the role of the mother's imagination in deviant births, 'Paget cites a case of a girl with a thick harsh crop of brown hair on back and arms who bore a striking resemblance to a monkey. The mother had received a sudden shock caused by the monkey of an organ-grinder springing upon her back' (Barr 1904: 96)" (125). Clare Clark's (2007) historical novel tells a story about an apothecary who tries to prove his theory of "the nature of monsters", based upon this hypothesis.

Barnaby is his mother's penance and also her solace in return for the shame and remorse that is otherwise the legacy of her marriage to a violent, irredeemable man.

The security of idiot characters like Barnaby Rudge and Willie Dixon is contingent upon the care of mother figures. McDonagh suggests this is because conventional wisdom at the time was that "women—less logical, but as a consequence slightly natural—provide the link, or perhaps the transition, between the world of idiot boys and that of rational adult men" (2008, 45). Despite the intellectual impairments of Susan's brother and Mary Rudge's son, and the sacrifices that both women make to preserve their security, the love that is bestowed upon Willie Dixon and Barnaby is clearly reciprocated. When Susan is away from home Willie is depicted as "moping in her absence—hanging listlessly on the farm-yard gate to watch for her. When he saw her, he set up one of his strange, inarticulate cries... and came towards her with his loose, galloping run, head and limbs all shaking and wagging with pleasant excitement" (Gaskell 29). He is sensitive to his sister's moods, as is Barnaby when he comes home to his mother "and putting his arms about her neck, kissed her a hundred times" (Dickens 147). Full of his own story of his day, he eventually realizes that his mother is disturbed: "'How pale you are to-night!' said Barnaby, leaning on his stick. 'We have been cruel, Grip, and made her anxious!'" (Dickens 148). When Barnaby does leave his mother, against her wishes, to join the political uprising, it is for her sake at least as much as his own, as he imagines the time

when these frays were over, and the good Lord had conquered his enemies, and they were all at peace again, and he and she were rich, what happiness they would have in talking of these troubled times when he was a great soldier; and when they sat alone together in the tranquil twilight, and she had no longer reason to be

anxious for the morrow, what pleasure would he have in the reflection that this was his doing—his—poor foolish Barnaby’s; and in patting her on the cheek, and saying with a merry laugh, ‘Am I silly now, mother—am I silly now?’ (Dickens 471)

Through numerous examples, Dickens and Gaskell both demonstrate how the affectionate devotion of their charges justifies the sacrifices that Mrs. Rudge and Susan Dixon make to keep Barnaby and Willie safe.

This does not mean that loving and caring for someone with severe mental disabilities is not wearing. At times even the caregiver’s personal safety and mental health are threatened by the dependence and the sometimes violent behaviours of the mentally disabled character. Rochester’s story particularly demonstrates the enormity of the care burden when there is no natural affection between the lunatic and her keeper. Joined in marriage, Rochester is the only family that Bertha can claim with any obligation to care for her,<sup>9</sup> and it is made clear that the union is indissoluble. He explains that “a nature the most gross, impure, depraved I ever saw, was associated with mine, and called by the law and by society a part of me. And I could not rid myself of it by any legal proceedings; for the doctors now discovered that *my wife* was mad” (Brontë 353; emphasis in original). Death is the only legal exit from such a union, and at his most hopeless point Rochester admits to have contemplated suicide to release him:

‘This life,’ said I at last, ‘is hell: this is the air—those are the sounds of the bottomless pit! I have a right to deliver myself from it if I can. The sufferings of

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<sup>9</sup> The depiction of mental disability within marital relationships is relatively rare at this time. Marriage of idiots and imbeciles would generally be frowned upon and perceived as unnatural. However, in *No Name* (1862) Wilkie Collins depicts a marriage between con-artist Colonel Wragge and his idiot wife, who he also marries for money. Mrs. Wragge is a simpleton, and pathetic figure, but also gentle and kind-hearted.

this mortal state will leave me with the heavy flesh that now cumbers my soul. Of the fanatic's burning eternity I have no fear: there is not a future state worse than this present one—let me break away, and go home to God!' (Brontë 355)

The reader sympathizes with Rochester's burden because his wife is so extremely depraved that his aversion to her and his despair seem only natural.

In fact, Rochester's relentlessly loathsome description of the 'madwoman in the attic' on all sides makes Jane's eventual call for pity for the woman, on the grounds that "[i]t is cruel—she cannot help being mad'" (Brontë 347), almost incredible.<sup>10</sup> When she tries to fortify Rochester's control over his desires by appealing to his duty as a husband, he takes offense at Jane's suggestion that he hates his wife because she is mad:

'...it is not because she is mad I hate her. If you were mad, do you think I should hate you?'

'I do indeed, sir.'

'Then you are mistaken, and you know nothing about me, and nothing about the sort of love of which I am capable. Every atom of your flesh is as dear to me as my own: in pain and sickness it would still be dear. Your mind is my treasure, and if it were broken, it would be my treasure still...'. (Brontë 347)

The implication is that it is not Rochester's duty to care for his wife that is intolerable; it is that he never loved his wife in the first place. The provision of compassionate care is understood to be dependent upon the establishment of a regard that pre-dates the affliction.

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<sup>10</sup> In hindsight, Brontë wrote to her editor that she regretted the demonization of Bertha, although she added that "there is a phase of insanity which may be called moral madness": however, 'profound pity out to be the only sentiment elicited by the view of such moral degradation... I have not sufficiently dwelt on that feeling. I have erred in making horror too predominant, Mrs. Rochester indeed lived a sinful life before she was insane, but sin is itself a species of insanity'" (Davies, Editor's Notes, 568-569).



While the reader sympathizes with Rochester's responsibility as husband to a lunatic wife, the selflessness required by a mother or a sister to commit her life to the care of a mentally deficient son or brother is portrayed as natural. Susan Dixon's anxieties are actually the reverse of Rochester's: while he resents his legal obligation for his wife's care, Susan lives in fear of being deprived of the right to be her brother's caregiver. Susan's authority as guardian is limited by her gender and her status as an unmarried woman. Even though Willie demonstrates the capacity to communicate his attachment to his sister, he has no right to choose his own living circumstances. Even Susan's guardianship could be overruled if her brother's occasional violent outbursts became known.

As eternal children, Willie and Barnaby's dependency instills a devotion to their family which, in turn, engages the nurturing capacities of their caregivers and gives them strength to persevere. In a fervent prayer, Barnaby's mother asks,

‘Oh Thou,...who hast taught me such deep love for this one remnant of the promise of a happy life, out of whose affliction, even, perhaps the comfort springs that he is ever a relying, loving child to me—never growing old or cold at heart, but needing my care and duty in his manly strength as in his cradle-time—help him, in his darkened walk through this sad world, or he is doomed, and my poor heart is broken!’ (Dickens 154)

As the child of her dead husband's beloved sister, Mrs Reed could perhaps have also found comfort in raising up the child according to her dying husband's final wish, but she is not a generous woman. Mrs Reed's treatment of Jane belies the assumption that parents and guardians will always act in the best interests of those for whom they are presumed to carry some filial attachment or moral obligation.

Both Gaskell and Dickens also depict how the vulnerability of simple-minded characters is exploited by those who should feel responsible for their care. Michael is physically abusive toward his prospective brother-in-law. In one instance, he kicks Willie for being clumsy and when Susan remonstrates with him for the assault, Michael goes off and gets drunk. Yet, when he is incapacitated the next day, it is noted that “Willie had far more pity on him than Susan. Before evening, Willie and he were fast... friends” (Gaskell 12). The simple and affectionate nature ascribed to the idiot is also apparent in Barnaby’s determination to see good in his loathsome father. Even when he recognizes him as the robber who had left his friend Chester for dead he still “put his arms about his neck, and pressed his head against his cheek” (Dickens 520). As Barnaby is very susceptible to any association that may make a claim on his duty and affections, once the rioters break open the jails to release the prisoners Barnaby cares for his unworthy father, in exile:

Heaven alone can tell, with what vague thoughts of duty, and affection; with what strange promptings of nature, intelligible to him as to a man of radiant mind and most enlarged capacity; with what dim memories of children he had played with when a child himself, who had prattled of their fathers, and of loving them, being loved; with how many half-remembered, dreamy associations of his mother’s grief and tears and widowhood; he had watched and tended this man. But that a vague and shadowy crowd of such ideas came slowly on him; that they taught him to be sorry when he looked upon his haggard face, that they overflowed his eyes when he stooped to kiss him on the cheek, that they kept him waking in a tearful gladness, shading him from the sun, fanning him with leaves, soothing him when he started in his sleep... (Dickens 566)

All the while, Barnaby is waiting on his mother to come and make their family complete. Rudge the father, however, is a most irredeemable character. Incapable of empathy, remorse or any redeeming human feeling, to the very last he does not repent his heinous crimes. Rather, he curses his long-suffering wife and their son because she will not lie to spare him the death sentence that he has already once eluded (Dickens 611-612). With his lack of conscience, or natural feeling, Rudge has more in common with Bertha Rochester than does Barnaby or Willie Dixon.

Relationships between the mentally disabled individual and his or her family are revealed to be more complex in Establishment novels than policy belonging to this phase of the Cycle indicates. There is a tendency to explain disability in terms of the family's moral degeneracy, where madness is perceived as a condition passed on from one generation to the next, or idiocy is an affliction upon the offspring as a result of the sins of the parent. Policy largely endorses these assumptions, yet also identifies the family as the most appropriate location of care for the mentally disabled individual. The first institutions for the care of lunatics and idiots in Upper Canada were originally perceived as a last resort for people who did not have family willing or able to support them. The fact that asylum admissions continued to exceed expansion is attributed to the moral degeneracy of the working classes. An interrogation of the ways that rapid social and economic change contributed to undermining traditional family roles and displacing many people would not occur for generations. As a result, it is not surprising that an institutional option is not portrayed as a positive solution from the perspective of good people like Mary Rudge and Susan Dixon. Rochester's position is more ambiguous, but by finally acting selflessly to risk his life to save that of his lunatic wife, he is rewarded by her demise, and the liberty to make a new family with the woman he loves.

## **Community Roles**

By the time a formal institutionalization policy was introduced, in 1839, mental disability was perceived to exist “completely within the individual” (McDonagh 2008, 4). In an age of rapid industrialization, the worth of the individual was increasingly conceived of in terms of his or her contribution to the waged labour market. People who could not compete in a capitalist economy were at best a burden on society. Eventually, with the growth of the eugenics movement in England and North America that was occurring by the turn of the century, they increasingly became perceived as a threat to the species. Families were expected to care for their vulnerable members, but as extended family networks were broken down as a result of urbanization an increasing number of people were destitute of the necessary personal daily living supports required to sustain them. Nineteenth-century social welfare policy generally perceives idiots as belonging to a larger population of vagrants and immoral characters. Community responsibility toward people with mental disabilities was defined in terms of their charitable contributions and the taxes that they paid to maintain houses of industry or poorhouses, and the insane and idiot asylums that were eventually established.

At the outset of the Establishment phase the Government of Upper Canada tried to put the responsibility for financing the difference between the costs of care and what families were able to pay onto municipalities. This, however, was not sustainable and over time it became incumbent upon the Province to pick up most of the costs. Before the first asylum dedicated to the care and control of idiots was established in Ontario, every municipality was required to erect a workhouse to contain the chronically unemployed or

indigent. The Act Respecting the Municipal Institutions of Upper Canada (1866)

empowered a Justice of the Peace, or his representatives to

commit to the House of Industry or of Refuge, to be employed and governed

according to the rules, regulations and orders of the House:

1. All poor and indigent persons who are incapable of supporting themselves;
2. All persons without means of maintaining themselves and able of body to work and who refuse or neglect to do so;
3. All persons leading a lewd, dissolute, or vagrant life, and exercising no ordinary calling, or lawful business sufficient to gain or procure an honest living;
4. And all such as spend their time and property in public houses, to the neglect of any lawful calling;
5. And idiots. (Sec. 414)

Criteria for distinguishing between categories of unemployable people were very arbitrary and inconsistent. This law, for instance, establishes no specific criterion for determining who is an idiot.

The fifth and final category of eligibility for the workhouse implies that the idiot is anybody with no inclination or capacity for gainful employment, who is not otherwise assigned to a preceding category. Upper Canada's first Provincial Lunatic Asylum opened in 1841. However, it was not until 1876 that the first asylum dedicated to the care of idiots would open in the Province, thereby acknowledging that idiots did not fit the general profile of people who could be coerced into self-sufficiency through enforced labour. That being said, a historical analysis of the living conditions of asylum residents reveals that these facilities relied very heavily on the uncompensated labours of inmates (Simmons, 1982, 103).

Policy reinforced the public's distinction between lunatics and idiots, although by the end of the nineteenth century this distinction was largely irrelevant in law.

Explanatory notes attached to Ontario's Act Respecting Lunacy explains that "[a]n idiot is one who never had reason, while a lunatic as distinguished from an idiot is a person who was of good and sound memory, and by the visitation of God, sickness, grief or accident, has lost it... The distinction between an idiot and a lunatic is now of no consequence, the word 'lunatic' comprising idiots and persons of unsound mind" (Bicknell & Kappele 243). In law, the terms and conditions of guardianship for idiots or lunatics were the same.

Given the increasingly hostile community environment for people who were unattached to the labour market, it is significant that Dickens and Gaskell both set their novels seventy and fifty years back in time, respectively. Although their mental disabilities still threaten their personal security, Willie Dixon and Barnaby Rudge are also able to claim a place in the small villages where their respective families have been long-established. The importance of the community is less explicit in Brontë's, *Jane Eyre*, as in many respects it is a story about isolation. Jane's own mental stability is threatened in childhood as a result of her personal isolation within a family who does not want her (Wood 96); and Bertha Rochester's madness, arguably, is exacerbated by her segregation from the rest of the world.

A considerable amount of Establishment-era policy pertaining to people with mental disabilities addresses the relationship between the individual and those people or agencies charged with their care. When Susan will not submit to Michael's terms concerning Willie's place in the family she asserts her brother's hereditary right to abide with her. She tells her fiancé, "I will not have thee, if thou say'st in such a hectoring

way that Willie must go out of the house—and the house his own too—before thou’lt set foot in it. Willie bides here, and I bide with him””(Gaskell 27). People deemed mentally incapable typically forfeit the right to manage their own financial affairs and estate. What Susan is declaring here is the enduring moral right that her brother has, even in his idiocy, to enjoy the avails of his hereditary entitlement.

In the novel, the disabled character is often used as a narrative device to illuminate the motives of other characters, or wider society (Davis, 1998, 328-329; Iyer 131; Mitchell & Snyder 205). In the nineteenth century “‘idiots’ increasingly become a measure of the goodness of their patrons; they are the objects of charitable acts that define the actors as responsible and morally worthy citizens” (McDonagh, 2008, 95). Mentally disabled characters are also sometimes used to illuminate the worst aspects of other characters. In Gaskell’s story, Michael Hurst’s abusive treatment of Willie and his lack of compassion make him the story’s villain. Having “long felt the boy to be a trouble... of late he had absolutely loathed him. His gibbering, his uncouth gestures, his loose, shambling gait, all irritated Michael inexpressibly” (Gaskell 25). In fact, on several occasions it is Michael who is revealed as the real disruptive element to the family peace and good management of the estate. When he begins to assume authoritative airs as the presumptive master of the farm, Michael’s abilities are called into question by the farm labourers, who remember him as

a stripling on the farm, knowing far less than they did, and often glad to shelter his ignorance of all agricultural matters behind their superior knowledge. They would have taken orders from Susan with far more willingness; nay, Willie himself might have commanded them; and from the old hereditary feeling toward the owners of the land, they would have obeyed him with far greater cordiality than they now

showed to Michael. (Gaskell 21)

Local tradition and hereditary respect for the Dixon family line purchase a degree of tolerance for Willie and establish a place for him in the community, despite his mental incapacity.

Still, Susan lives in fear of having Willie taken from her care without her consent, in the event that she cannot keep his behaviours contained: “above all, she dreaded lest some one might find out in what danger and peril she occasionally was, and might assume a right to take away her brother from her care. The one idea of taking charge of him had deepened and deepened with years. It was graven into her mind as the object for which she lived” (Gaskell 37). This is why she feels compelled to do better than merely get by. Her personal conduct and domestic management must be perceived as being above reproach in order to secure Willie’s place on the family farm and within the community.

Dickens’ novel also portrays how important community-belonging is for people with mental disabilities. When Barnaby and his mother are forced to leave their home in order to escape his father, he suffers more in their exile than his mother, who understands why they need to live secretly in order to attain peace and some degree of security. While their humble income is diminished by lack of adequate employment to sustain them, Barnaby also becomes socially impoverished because “[f]ew in that place, even of the children, could be idle, and he had no companions of his own kind” (Dickens 371). Where he comes from, “[t]he people all knew Barnaby, and the children of the place came flocking round him—as [his mother] remembered to have done with their fathers and mothers round some silly beggerman, when a child herself. None of them knew her” (Dickens 209) now because her world has been much smaller, preoccupied with maintaining a home and providing for her son. Therefore, when Barnaby and his mother



happen upon the gathering of Lord Gordon's troops, Barnaby is seduced by the spirit of camaraderie that the cause inspires in him as he attaches his blue cockade to his hat "with an air of pride" (Dickens 298), as well as the promise of riches to relieve his mother's poverty and make a happier life for them both.

Barnaby does not really understand the Gordon cause, which occurred in 1780 as a result of "agitation against the Catholic Relief Act... Opposition to the Act was coordinated by the Protestant Association, of which Gordon was President" (Bowen 710-711). The attraction of the uprising, for Barnaby, is the sense of belonging that his compatriots give him. When Hugh gives him a banner to carry at the head of their regiment, Barnaby becomes

[f]orgetful of all other things in the ecstasy of the moment, his face flushed and his eyes sparkling with delight heedless of the weight of the great banner he carried, and mindful only of its flashing in the sun and rustling in the summer breeze, on he went, proud, happy, elated past all telling:-- the only lighthearted, undesigning creature, in the whole assembly. (Dickens 404-405)

His only regret is that his mother is not present to see him in his glory. Barnaby does not understand that the cause he has signed on for will imperil his friends and cause terrible loss and grief to innocent people. Because of his innocence he trusts easily in the goodness of others who welcome him in their midst.<sup>11</sup>

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<sup>11</sup>For Dickens it makes sense that Barnaby experiences a sense of belonging among those who would bring down the Government because revolution is a kind of madness. Even though Dickens satirizes the leadership on either side of this uprising, the better men are aligned with the forces of stability and order, which is what government aspires to symbolize. Bowen reads *Barnaby Rudge* "as one of the more conservative of Dickens's works" (xxv) because of its "treatment of popular insurrection". However, a similar ambivalence is evident in *Hard Times* where Dickens depicts a very vivid and heartbreaking story of the working conditions of factory "hands", but also represents a fledgling union movement as reckless and uninformed. He endorses a liberal humanist tradition that critiques the injustices of the prevailing political

Barnaby's innocence wins him protectors on both sides of the uprising. However, the most substantial indicator of Barnaby's value in the community is the lengths that the good locksmith, Gabriel Varden, goes to in order to save Barnaby from being hanged following the Gordon Riots. He assures his friend, Haredale, that Barnaby's mother will have a home and a friend in him,

‘...but Barnaby—poor Barnaby—willing Barnaby—what aid can I render him?

There are many, many men of sense, God forgive me,’ cried the honest locksmith, stopping in a narrow court to pass his hand across his eyes, ‘I could better afford to lose than Barnaby. We have always been good friends, but I never knew, till now, how much I loved the lad.’ (Dickens 633)

Even Hugh, who has manipulated Barnaby into participating in the uprising and has no legitimate claim for mercy to be exercised on his own behalf, commits his final words to absolving Barnaby of blame, as he stands before the noose: ‘I’ll say this,’ he cried, looking firmly round, ‘that if I had ten lives to lose, and the loss of each would give me ten times the agony of the hardest death, I’d lay them all down—ay I would, though you gentlemen may not believe it—to save this one. This one,’ he added, wringing his hand again, ‘that will be lost through me’” (Dickens 646). When Barnaby attempts to remonstrate, Hugh gestures to the attending clergyman and explains how he ““has often in the last few days spoken to me of faith, and strong belief. You see what I am—more brute than man, as I have been often told—but I had faith enough to believe, and did believe as strongly as any of you gentlemen can believe anything, that this one life would

be spared”” (Dickens 646); and in fact, at the very last moment, Varden does win Barnaby’s release.

However, in the sample considered here, the positive outcomes that do occur are revealed to have more to do with the strength of individual characters than they do with the inherent justice of government systems and their policies. Dickens, in particular, makes a point of demonstrating that it is only good fortune and the perseverance of a worthy citizen that spares Barnaby from being hanged, following the Gordon Riots. In fact, he depicts a justice system that exercises its harshest sentences on those least able to defend themselves. Describing the scenes that Barnaby passes en route to his own imminent execution Dickens describes how

[t]wo cripples—both mere boys—one with a leg of wood, one who dragged his twisted limbs along with the help of a crutch, were hanged in this same Bloomsbury Square. ... Another boy was hanged on Bow Street; other young lads in various quarters of the town. Four wretched women, too, were put to death. In a word, those who suffered as rioters were for the most part the weakest, meanest and most miserable among them. (Dickens 648-649)

In the end, Dickens is critical of the political status quo even while he deplores the lawlessness of the riots. Barnaby’s reprieve is not meant to be seen as justice tempered with mercy, as it is made clear that had he been truly alone in the world, without the support of people of status and influence, then he would have been executed for actions he committed without directly causing any bodily harm to anyone, and without really understanding their implications.

The conclusion of Barnaby’s story is especially fortuitous when contrasted with the other disabled characters considered in this selection whose storylines end in death.

In fact, the death of the disabled character often means liberty for those who carry the burden for their care.<sup>12</sup> When Jane returns to Thornfield, a year after her flight, she finds it burned to the ground. In response to her inquiries, the local inn-keeper describes how Rochester

‘...went back to get his mad wife out of her cell. And then they called out to him that she was on the roof, where she was standing, waving her arms above the battlements, and shouting out till they could hear her a mile off: I saw her and heard her with my own eyes. She was a big woman, and had long black hair: we could see it streaming against the flames as she stood. I witnessed, and several more witnessed, Mr Rochester ascend through the sky-light on to the roof; we heard him call “Bertha!” We saw him approach her; and then, ma’am, she yelled and gave a spring, and the next minute she lay smashed on the pavement.’ (Brontë 493)

Jane returns to a humbled man, blinded and maimed by the fire that destroys the impediment to their union. For her part, Jane admits relief at learning the extent of the disabling injuries that he suffered: “I had dreaded worse. I had dreaded he was mad” (Brontë 494). With his beloved restored to him, Rochester gives thanks to a God that is merciful as well as just (Brontë 516). Unlike Barnaby Rudge and Willie Dixon, Bertha’s madness is so completely debilitating that she cannot generate any sympathy from other characters in the novel, or even the reader. Furthermore, because she is unable to tell her own story, has no sympathetic advocate, or real presence in the community her loss is

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<sup>12</sup> As the Establishment phase progresses, the prospects for idiots and imbeciles becomes even more bleak as the realistic novel continues to evolve. Critically acclaimed examples include, Joseph Conrad’s *The Secret Agent* (1907) and John Steinbeck’s *Of Mice and Men* (1937). Both authors create worlds so hostile to their mentally disabled characters that they die violent deaths. A notable exception to this trend is William Faulkner’s tragic family saga, *The Sound and the Fury* (1929) where the idiot brother suffers, but survives his beautiful sister and gifted brother.

mourned by no one. Therefore, when she finally dies by fire, the response is to celebrate the removal of the obstacle to Jane and Rochester's union.<sup>13</sup>

Willie eventually dies of physical exhaustion as a result of a particularly intense and prolonged fit that takes Susan's endurance nearly to its limit. She "wrestled in prayer that somehow it might end before she, too, was driven mad; or, worse, might be obliged to give up life's aim, and consign Willie to a madhouse. From that moment of prayer... Willie calmed—and then he drooped—and then he sank" (Gaskell 38). Finally at rest, "she knew that to him death was no enemy, but a true friend, restoring light and health to his poor clouded mind" (Gaskell 38). However, like many people who devote their lives to the care of a loved one with severe disabilities, the responsibility often threatens to consume their whole identity. So, where Rochester experiences profound loneliness in his marriage, when Willie dies Susan loses her last remaining human tie. Therefore, the end of Willie's story, is also nearly the end of Susan's, as without her brother to care for her life has lost its purpose.

Her happy ending comes when she discovers Michael collapsed in a snowstorm and returns his body to his own family whom she finds living in poverty and neglect. The strain of Susan's load finally culminates in her own collapse, upon suffering a stroke at the widow's door. Revived by the compassion of the woman who "laid her on her own bed, and weeping silently for her own lost husband... nursed Susan like a sister"(Gaskell 47), Susan finally learns how to be cared for, herself:

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<sup>13</sup> Although not explored in Brontë's construction of Bertha Rochester, Rhys' (1966) prequel, *Wide Sargasso Sea*, constructs a life story for the 'madwoman in the attic' that explains her rage as a result of personal losses, and her incarceration in a foreign land. Otherwise, Bertha's raving is largely incomprehensible, apart from an apparent aversion to the woman who would usurp her place as Mrs. Rochester. Bertha has also been interpreted by feminist theorists as Jane's avatar, or her "truest and darkest double" (Gilbert & Gubar 360) who acts out Jane's repressed resentments and anxieties. At the very least she is a warning to Jane of the consequences of being guided by passion, unrestrained by reason.

Susan, lying still and motionless, learned much. It was not a severe stroke; it might be the forerunner of others yet to come, but at some distance of time. But for the present she recovered, and regained much of her former health. On her sick-bed she matured her plans. When she returned to Yew Nook, she took Michael Hurst's widow and children with her to live there, and fill up the haunted hearth with living forms that should banish the ghosts. (Gaskell 47)

Like Rochester, Susan needs to become physically disabled in order to learn how to live in reciprocal affection where she is not always the benefactor or caregiver. Physical incapacitation compels Rochester and Susan to be dependent on others, and this reminds the reader that none of us are immune to the loss of faculties or abilities that are easy to take for granted.

In all of the novels considered here, the isolation and losses suffered as a result of being assigned responsibility for the mentally disabled character's well-being are eventually rewarded with reconciliation with others, and re-integration into the wider community. Willie's idiocy is ultimately the saviour of his sister and the farm. It is the cause of the irreconcilable breach between Susan and Michael, which turns out to be fortuitous, given Michael's profligate and irresponsible temperament. Finally, the representation of Barnaby Rudge as an idiot who is involved in family secrets, the ordeals of crossed lovers, and political intrigues offers unique insight into dysfunction within families, community and the larger political system. The portrayal of an idiot character with such an extensive network of relationships and place in the community is quite radical within this phase of the Institutional Cycle.

### **Perceptions of the Institution**

The institution is understood here as all those facilities that housed people with mental disabilities, as well as other facilities that are utilized for the care and control of unwanted individuals. The government of Upper Canada originally tried to legislate that all municipalities provide some sort of poor house to provide shelter and the basic necessities of life for people who could not or would not care for themselves, as articulated in the Act Respecting Municipal Institutions of Upper Canada, 1866. However, over time it became impracticable to enforce this measure, as some jurisdictions simply pleaded lack of resources to maintain their elderly and feeble-minded. The Provincial Lunatic Asylum that was first established in London was under constant pressure to accommodate more people, and expansion was inevitable and rapid. By 1897 Ontario's social welfare system was established to the point that the Medical Superintendent for the Hamilton Asylum for the Insane addressed a meeting of the British Medical Association full of pride in the "vast provisions made by the State for the care and comfort of the defective classes" (J. Russell 3). He traces the rapid expansion of the asylum system in Ontario, pointing out that just

[s]ince 1871 there have been practically four new asylums erected in different parts of the Province, with a capacity of 2,700, not to speak of additions that have been made to the two older asylums, all erected and maintained at the expense of the Province. No nobler tribute could be paid to the wisdom, the generosity and the beneficence of the Government than the ample and splendid provision which has been made for the defective classes in this Province. (7)

Such high praise for the institutional system expressed by the state and its advocates in the medical community contradicts the asylum's cultural legacy. In fact, the Establishment-era novel is, at best, ambivalent about the benefits of institutional treatment for people with mental disabilities.

As the first institutions established for the care of idiots were being established, most readers of English literature would have been familiar with the Bethlem Hospital, commonly known as Bedlam. The oldest institution for the insane had a notorious reputation since the eighteenth century (Scull 59). In *Barnaby Rudge*, Dickens vividly depicts days and nights of rioting, destruction of property and violent death; however, what inspires the greatest public terror is a rumour

which diffused a greater dread all through London, even than these publicly-announced intentions of the rioters, though all men knew that if they were successfully effected, there must ensue a national bankruptcy and general ruin. It was said that they meant to throw the gates of Bedlam open, and let all the madmen loose. This suggested such dreadful images to the people's minds, and was indeed an act so fraught with new and unimaginable horrors in the contemplation, that it beset them more than any loss or cruelty of which they could foresee the worst, and drove many sane men nearly mad themselves. (Dickens 557)

Given the fear and loathing that Bedlam inspired in London's citizenry it is hardly surprising that people had reservations about the efficacy of an asylum system dedicated to the care of idiots, much less the security of relatives placed there.

The inability to reconcile their disagreement over the proper place for Willie Dixon is what finally breaks off his sister's engagement with Michael Hurst. Susan's absolute rejection of the idea of having her brother admitted to an institution is



rationalized by the narrator of *Half a Life-time Ago* in terms that go beyond filial attachment: “The country-side was full, in those days, of stories of brutal treatment offered to the insane; stories that were, in fact, but too well founded, and the truth of one of which only have been a sufficient reason for the strong prejudice existing against all such places” (Gaskell 26). Originally published in 1855, it is interesting to speculate about Gaskell’s narrative purposes in setting the story “half a lifetime”, or fifty years past. Institutions for idiots had only been recently established at the time of Gaskell’s writing (McDonagh 2008, 195). It is interesting that Dickens and Gaskell both set their stories in the past, and their characters reside in small villages. Possibly their intent is to enhance verisimilitude by setting their characters in a time and place where an idiot could more readily be accepted within the community.<sup>14</sup>

Once a policy of institutionalization was formalized, administrators began to perceive an alarming increase in idiocy and insanity in the general population. It is difficult to obtain reliable statistics for the beginning of the Establishment phase in Ontario; however Dr. James Russell reported that “[i]n the Province of Ontario the census and Provincial returns show an increase of population from 1871 to 1895 of 36 per cent., while the increase of insane for the same period is 245 per cent” (6). Similar rates of increase were being reported in the United States and England. As a result, debate ensued about whether this increase was attributable to better diagnosis and reporting, or if there were environmental explanations for this phenomenon. Dr. Russell argues that the rapid industrialization of the times is an important contributing factor to rising rates of insanity:

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<sup>14</sup> Other novels by the authors considered in this phase of the Cycle more specifically address the writers’ impressions of contemporary social, familial and economic systems, and how they were being impacted by rapidly expanding industrialization, urbanization and capitalism. Brontë’s *Shirley* (1849), Dickens’ *Hard Times* (1854) and Gaskell’s *North and South* (1855) are examples.

It cannot be denied that a large percentage of the human family is born into the world so weakly endowed mentally as to be wholly unfit for anything but the most primitive form of citizenship. With quiet and uneventful surroundings, which do not overtax their mental energies, they manage to pass through life in the undisturbed possession of their meagre mental outfit with comparative ease and comfort, but the moment they are subjected to complex conditions of life which require greater mental and physical activity to gain a subsistence, they weaken and falter by the way and gravitate into the vagrant and pauper ranks, which are the great recruiting camps from which we draw the great army of pauper insane. (8)

However, in literature from the commencement of the Establishment era, the impact of rapid industrialization on the lives of people with mental disabilities can only be inferred.

The establishment of an institutional policy system marks a cultural shift in attitudes about mental disability. Dickens sets his novel seventy years in the past, and Gaskell looks back fifty years to situate their characters in rural communities where the ‘village idiot’ could still claim a place. However, each of the novels also debate the role of the institution as it was emerging at the time. In different ways, each of the novelists considered here is wrestling with a transition from a tradition that saw people with mental disabilities as members of the community, to the growing influence of a perspective that advocates for their segregation.

The idiot asylum system commenced with an original mandate to train idiots up to a functional level where they might sustain themselves in wider society (McDonagh 2008, 195; Radford & Park, 5-6). The rapid expansion of the asylum system, however, demonstrates that this often did not occur, even in those asylums erected for the care and

control of the “curably insane.”<sup>15</sup> The steady growth in the rate of institutionalization does not reflect the moral debate that surrounded the decision to place a family member in the institution. Establishment era novels portray great skepticism about the quality of institutionalization and the appropriate location of care for people with mental disabilities.

The debate in Gaskell’s *Half a Life-Time Ago*, about how to deal with Willie Dixon’s mental disability, speaks to the reputation of the asylum amongst the public, while also revealing the true natures of the primary characters in the story. Michael’s pre-emptive move to get a referral for Willie to an idiot asylum, “or madhouse, as they were called in that day and place” (Gaskell 25), is for self-interested purposes that are poorly disguised as concern for Willie’s well-being. Because Michael’s motives for getting rid of Willie are selfish, his actions reveal his own defective character. Therefore, it is difficult to determine whether his representation of the doctor’s advice is reliable when he asserts that the “doctor thinks he will get badder from year to year. And he said if he was us—you—he would send him off in time to Lancaster Asylum. They’ve ways there both of keeping such people in order and making them happy” (Gaskell 24). Because he is not a trustworthy character, and because of his undisguised aversion to Willie, Michael’s advocacy for an institutional solution for Willie’s care is intended to be read as a bad choice.

People’s attitudes about the asylum are also enmeshed with how they perceive their obligation to the disabled individual. Rochester does not offer an explicit reason for not having his wife placed in an asylum; however, there is historical evidence that

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<sup>15</sup> Reaume finds that over the course of the first century of its existence (1846-1940) the discharge rate for men from the Toronto Hospital for the Insane was about 50.26% for men, and 55.25% for women, including deportations to other institutional facilities. Simmons indicates that the number of “Mentally Retarded People in Provincial Institutions” rose almost continuously from the time that these statistics were kept in 1872” (1982, 314-318).

institutionalization was a less attractive option for people who had the means to consider alternatives. Near the end of the nineteenth century, Russell explains that the

increase in pauper lunatics [in England and Wales] from 1859 to 1896 was from 31,401 to 87,417, while the increase in the private class has only been from 4,679 to 8,265... The Commissioners draw a marked distinction to the ratio of increase between private and pauper lunatics, and report that the number of private lunatics is actually lower in 1896 than in 1879, and is still undergoing annual diminution.

(5-6)

It is likely that the ability to acquire private care services also allowed the rates of the “private” lunatic population to go under-reported.<sup>16</sup> Wealthier classes had the means to make the kind of care arrangements to allow them to maintain their privacy and shield them from the stigma associated with having madness in the family. Therefore, it makes sense that Rochester would have shunned institutionalization as the best recourse for a wife whose existence he did not want to acknowledge.

Although Brontë’s novel makes no direct attempt to cast aspersions on the quality of institutional care, it was generally perceived as an option of last resort for families of all classes (McDonagh, 2008, 223), as portrayed in Gaskell’s story. Mrs Poole’s character sketch, abbreviated as it is, alludes to the toll that the work exacted from those who were employed as attendants in these facilities, as well. When the local inn-keeper

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<sup>16</sup> In Ontario, Simmons explains that “[t]he fact that a certain number of beds were set aside for the wealthier patients at the PLA whereas this was not the case at Orillia [idiot asylum] is indirect proof that Orillia was unlikely to attract those who could pay their expenses. Another determining factor against sending those who could pay to Orillia was the differentiated treatment accorded to the patients at Orillia as compared to those at Toronto, or, even more important, with mentally retarded people at the New York State Asylum for Idiots at Syracuse... [E]vidence is lacking, but it is likely that many Canadians who could afford the cost, sent their children or relatives to the New York Asylum where treatment and conditions were so much better than at Orillia”. (1982, 36-37)

gives Jane the details surrounding the fire that destroyed Thornfield he explains how Bertha “had a woman to take care of her called Mrs Poole—an able woman in her line, and very trustworthy, but for one fault—a fault common to a deal of them nurses and matrons—*she kept a private bottle of gin by her*, and now and then took a drop overmuch. It is excusable, for she had a hard life of it” (Brontë 492 emphasis in original). Although it is possible that Grace Poole’s hard life may have been an outcome of other circumstances, apart from the nature of her employment, the historical evidence shows that the working conditions for caretakers of idiots and lunatics were generally poor.

Upper Canada’s system of institutional care was largely modeled after England’s policy. In fact, “ideas about policy were widely shared by authorities in Canada, the U.S. and Great Britain” (Simmons, 1982, 50). Research cited by Simmons indicates that personal attendants at Orillia fared worse than their counterparts in the United States: “the dramatic economies obtained in Ontario as compared with the American Asylums came from paying personnel, both superintendents and staff, much less than elsewhere, by having few staff for many patients, and by feeding the patients a monotonous and tasteless diet” (1982, 33). Simmons points out that “[i]n 1883, inspector O’Reilly noted that the average monthly wage for attendants in the United States was \$73.82 while in Ontario it was \$29.32” (1982, 33).<sup>17</sup> Walter Williston also speaks to how, historically, institutional staff were chronically “overworked, undertrained, and underpaid” (24).

However, regardless of the conditions of work and level of compensation, in his historical analysis of patient life at the Toronto Hospital for the Insane, Reaume also stresses that

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<sup>17</sup> In his work dedicated specifically to mental health policy in Ontario from 1930-1989, Simmons further contends that in the 1930s hospital staff had to cope with similar capacity pressures as experienced in the asylum designated for idiots, coping “on a day-to-day basis with enormous and increasing numbers of people suffering from a wide variety of mental and physical illnesses, often behaving in a bizarre, disruptive or violent fashion. It is no wonder that, lacking any other means, staff sometimes resorted to brute force and violence or to mechanical restraints in order to deal with difficult patients” (1990, 15)

these circumstances can not excuse abuses that were perpetrated against vulnerable patients (74).

Apart from the anxieties that many people had about relinquishing the care of loved ones to an asylum system of such dubious reputation, many others were skeptical about the wisdom of providing any social welfare support for people with mental disabilities. Dickens depicts this position in *Barnaby Rudge* in a scene where Barnaby and his mother encounter a country lord who arrests them on their journey:

when the gentleman appeared disposed to exercise his horsewhip, the widow ventured to inform him in a low voice and with tears in her eyes, that her son was of weak mind.

‘An idiot, eh?’ said the gentleman looking at Barnaby as he spoke. ‘And how long hast been an idiot?’ ...

‘From his birth,’ said the widow.

‘I don’t believe it,’ cried the gentleman, ‘not a bit of it. It’s an excuse not to work. There’s nothing like flogging to cure that disorder. I’d make a difference in him in ten minutes, I’ll be bound.’

‘Heaven has made none in more than twice ten years, sir,’ said the widow mildly.

‘Then why don’t you shut him up? we pay enough for county institutions, damn ’em. But thou’d rather drag him about to excite charity. Ay, I know thee.’

(Dickens 389-390)

For as long as there has been any kind of social welfare system to provide relief to the poor, sick, unemployed and unemployable, there has always existed a suspicion and fear that people will rely on such supports to avoid working to support themselves. This is the

rationale for a policy of less eligibility. By making the conditions of poorhouses and other public institutions so materially deprived, the authorities ensured that the institution must always be an option of last resort (Rice & Prince 34-35). This attitude at least partially explains the public distaste for the institutional system, even as the Establishment period progressed and it was actively promoted as the most appropriate treatment for lunacy and the care of idiots.

Bertha is incarcerated because of her madness, but Jane has also been incarcerated for most of her life before going to Thornfield: first as a lonely and abused ward in the Reed household, and then as a student at the Lowood Charitable Institutional School for poor and orphaned girls. Brontë, in fact, suggests that this isolation threatens Jane's own sanity. When she becomes ill as a result of the "fit" she experiences while locked in the "red room," the attending apothecary gains insight into the child's living situation within the Reed household; and he recommends that Jane be sent away to school because her "nerves are not in a good state" (Brontë 31). She is soon dispatched to Lowood School.

Jane gives a detailed description of her first impressions of the unhealthy living environment at Lowood, which are heavily influenced by Brontë's own childhood experience of boarding at a school for clergymen's daughters:<sup>18</sup>

A stone tablet over the door bore this inscription:-

‘Lowood Institution.- This portion was rebuilt A.D.--, by Naomi

Brocklehurst, of Brocklehurst Hall, in this county.’ ‘Let your light shine before

men that they may see your good works, and glorify your Father which is in

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<sup>18</sup>This section of the novel demonstrates how even fiction stories can often be traced back to events in an author's personal life story. Chapter IV of Elizabeth Gaskell's (1857) biography, *The Life of Charlotte Brontë*, goes into detail about the similarities between Jane's time at Lowood School and Brontë's own experience at Cowan Bridge where her elder sisters, Maria and Elizabeth contracted the consumptive illness from which they died, shortly after their removal. Gaskell speculates that Charlotte's stunted growth may be attributed, at least in part, to the deprived, semi-starved circumstances that she experienced at the school.

heaven.’—St Matt.v. 16.

I read these words over and over again. I felt that an explanation belonged to them, and was unable fully to penetrate their import. I was... pondering the signification of ‘Institution,’ and endeavouring to make out a connection between the first words and the verse of Scripture... (Brontë 58-59).

When Jane asks Helen Burns, “‘why do they call it Institution? Is it in any way different from other schools?’” (Brontë 59), Helen explains that it is an institution for educating orphans. Most of the children do not have access to sufficient funds to pay their board, nor do they have anyone to care much about whether they are provided for.

Another explanation for the deprivations of institutional life was that charity should aspire to nurture humility and fortify the spirit for the low station in life to which inmates could realistically expect to aspire. Lowood School imposes stringent economies at the expense of the health of its charges. The living conditions described by Jane in chapter VI are not dissimilar to the impressions recorded by J. H. Tuke, following his visit to the Provincial Lunatic Asylum, in Upper Canada, on September 30, 1845:

It is one of the most painful and disgusting places I ever visited... There were perhaps seventy patients upon whose faces misery, starvation and suffering were indelibly impressed. The doctor... pursues the exploded system of constantly cupping, bleeding, blistering and purging his patients, giving them also the smallest quantity of food and that of the poorest quality... (In Simmons 1982, 4)

Jane Eyre recalls in detail the experience of being constantly hungry and yet often unable to eat the burnt or rancid rations that were served to the students at Lowood School (ch VI-VII).



The intended purpose of the asylum was to rehabilitate and cure. Likewise, Jane is ostensibly sent to this institution to cure her of her wicked ways. As Brocklehurst introduces her officially to the assembly of students and teachers he publicly condemns Jane as a liar, on the basis of the testimony he has received from Mrs Reed:

‘This I learned from her benefactress—from the pious and charitable lady who adopted her in her orphan state, reared her as her own daughter, and whose kindness, whose generosity the unhappy girl repaid by an ingratitude so bad, so dreadful, that at last her excellent patroness was obliged to separate her from her own young ones, fearful lest her vicious example should contaminate their purity. She has sent her here to be healed, even as the Jews of old sent their diseased to the troubled pool of Bethesda; and, teachers, superintendent, I beg of you not to allow the waters to stagnate round her.’ (Brontë 79)

The educational emphasis is placed on her moral rehabilitation rather than her intellectual accomplishment. Again, this is similar to the trend within the lunatic asylums of the time to replace physical coercion with a system of “moral treatment”<sup>19</sup> to induce compliance with societal dictates about what constituted proper behaviour, according to one’s station in life (Reaume 11, 14; Scull 16-17).

Jane experiences a healthier standard of living once “the typhus fever had fulfilled its mission of devastation at Lowood... [and] its virulence and the number of its victims

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<sup>19</sup> Reaume explains that “[m]oral therapy originated with the work of Philippe Pinel in France and William Tuke in England in the late eighteenth and early nineteenth centuries. They initiated the movement away from the most physically coercive forms of confinement and emphasized instead trying to instil self-discipline and a firm ‘guidance’ over the behaviour of their charges through moral suasion. This effort to promote essentially middle-class standards of conduct on people in mental institutions, such as ideas about respectability and a regular daily routine, influenced asylum keepers throughout the Western world, where larger and increasing numbers of mental institutions were being established. As with their British and American counterparts who had earlier used the ideas of Tuke and Pinel to try to move away from physical coercion, Joseph Workman, Superintendent [of the Toronto Hospital for the Insane] from 1853 to 1875, and Daniel Clark (1875-1905) both saw this approach as more humane” (11).

had drawn public attention to the school. Inquiry was made into the origin of the scourge, and by degrees various facts came out which excited public indignation to a high degree” (Brontë 99). This part of Jane’s story seems to anticipate a pattern in the Institutional Cycle where neglect and abuse of vulnerable people is allowed to progress until a crisis occurs that draws public attention to the segregated lives of people who, generally, have few advocates. Public exposure of the living conditions at Ontario’s Hospital School in Orillia will later lend momentum to the Reform phase of the Cycle.

## **CHAPTER 7- Analysis of Reform Phase (1960-1986)**

### **Introduction**

After 120 years of institutional establishment and steady expansion, a combination of pressures finally brought about a shift in the Institutional Cycle from the Establishment to the Reform phase. This transition cannot be linked to the introduction of any one specific policy act or narrative. The Ministry of Community and Social Services indicates that the “community living movement [was] originally started by parents in the mid-1950s to integrate their family members more fully in the community” (Government of Ontario, 2006, 5). However, throughout the course of the long Establishment period there were always dissenting voices who lobbied for greater opportunities for people with mental disabilities.<sup>20</sup> Parents especially advocated for educational opportunities for feeble-minded and idiot children who were, by this time, more consistently defined as mentally retarded or handicapped (Simmons 1982, 145). Still, the Province’s large institutional facilities kept growing, and growing more crowded. Except for family members who tried to maintain active involvement in the lives of their relations residing at the Orillia Hospital, the Rideau Centre or the other long-term institutional facilities for

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<sup>20</sup> For example, on Sept. 29, 1948 the *Toronto Daily Star* published the following letter, written by Mrs. V.B. Glover: “May I say a few words on behalf of our backward children, and their bewildered mothers. There is no school for such children, no place where they could get a little training to be of some use in the world, only Orillia, which is always full. If these children can be taught something at Orillia, why cannot a day school be put at their disposal? I am sure their mothers would gladly pay for their transportation to and from school. After all, they are paying taxes for other, more fortunate children’s schooling. I think it is time something was done for parents, who, from a sense of faith and hope in a merciful providence wants to keep them at home, living a normal life. These are real parents only asking a little aid and encouragement to shoulder their own heavy burden...”.

people with disabilities in the Province, the general public was largely unaware of what life was like for people living in the institution.

This changed for many when Pierre Berton published his regular column in the January 6, 1960 edition of the *Toronto Star*. Entitled “What’s Wrong at Orillia: Out of Sight—Out of Mind,” he spoke to the issues of structural deterioration and overcrowding at Ontario’s oldest institution for the mentally retarded:

[t]here are 4000 names on file at Orillia—names of people who have applied to enter a retarded child in the institution. The active waiting list—of people who have written within the last year—is 1500...

In 1949 Orillia admitted 196 new patients. In 1959 the number had grown to 310. At the present time they are coming in at the rate of three a day. The hospital loses, by death or discharge, less than half the number it admits annually. And so the terrifying problem builds up every year.

There are several reasons for this. One, obviously, is the population increase: for every 200 children born this year in Ontario, three will need institutional care. Ironically, too, medical advances have almost doubled the lives of many mentally retarded patients. The big move to the cities has made it difficult to care for a retarded child at home, and the ‘village idiot’ of our forefather’s day is likely to be a patient at Orillia now. Finally, because of a change in public attitudes, people seek out institutions which they once shunned. (31)

Public and political response to this column contributed momentum to a growing community living movement in the Province, and this chapter speaks to many of the issues raised by Berton.

As Ontario's hospital schools came under closer scrutiny, the government became increasingly interested in looking for policy options that would better serve the needs of residents and alleviate government's direct responsibility for the care of people with mental disabilities. In the 1970s, a number of reports were commissioned to find a way out of the institutional system for government and residents. Some of these, like the 'Williston Report' (1971), were commissioned by the Ontario government in response to specific incidents resulting in death or serious injury to individuals under the care of institutional facilities (3). The 'Welch Report' (1973) subsequently announced a "new policy focus for the delivery of services to the mentally retarded centred around the concept of community living" (i). However, this new objective could not be realized without first building community capacity to provide the services and supports currently delivered within the institutional system.

In fact, in the years immediately following Berton's damning exposé, admittance to hospital schools for the disabled continued to rise (Simmons 1982, 312-313). It was not until 1964 or 1965 that the total population of residents across sixteen facilities, in Ontario, finally peaked at 2,916 residents (Marshall 33). The number of institutional facilities grew because the initial impetus of the Reform movement was to shift to smaller, regional centres before beginning to actively expand community (nongovernmental) capacity. As a result, by the mid-1970s, Ontario had nineteen Schedule 1 (government-operated) institutions (Government of Ontario, 2006, 5).

A similar trend was occurring in provincial psychiatric facilities in Ontario, as many of these asylums housed substantial populations of seniors with chronic conditions, and little prospect of recovery (Simmons, 1990, 109-120). Dramatic reductions in the number of people residing in provincial institutions began to occur over the final ten years

of the Reform period when the number of people being “served in the community-based system grew from approximately 4,600 to more than 25,000” (Parsons 5) in anticipation of the Dismantlement phase of the cycle.

The other significant policy shift related to disability services planning came about as a result of the transfer of disability policy planning from the Ministry of Health to the Ministry of Community and Social Services, under the auspices of the Developmental Services Act, in 1974 (Government of Ontario, 2006, 5). This transfer reaffirmed the tradition of planning that aspired to develop separate service systems for people diagnosed as mentally disabled and mentally ill, despite Williston’s finding that the psychiatric and retarded were still co-habiting in the same facilities (31).

This transfer of responsibility from Health to Social Services ministries may have been perceived as progressive by some disability rights advocates who took issue with having cognitive impairments perceived as illness and disease, as well mental health advocates who promoted recovery from mental illness as an outcome not consistent with a disability diagnosis.<sup>21</sup> In reality, the incentive for the move was to make disability services meet the criteria for federal funding through the Canada Assistance Plan (CAP) initiative (1966), whereby the federal government pledged to match provincial investment in social services programming dollar for dollar (Simmons, 1982, 207).<sup>22</sup> On the other hand, this transfer of ministerial responsibility did little to facilitate coordination of services for people who were directly affected by policies generated now by separate bureaucracies.

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<sup>21</sup> In his report, Sen. Kirby explains that “[r]ecovery is about hope... recovery does not necessarily equate with cure. It can mean different things to different people. Very broadly, it suggests that the goal of mental health policy should be to enable people to live the most satisfying, hopeful, and productive life consistent with the limitations caused by their illness” (45).

<sup>22</sup> CAP was replaced by the Canada Health and Social Transfer in 1996, eliminating this cost sharing incentive for provinces.

A lot of novels published over the course of the Reform period reflect a growing awareness of the rights of people with mental disabilities and their status in society. Ken Kesey's *One Flew Over the Cuckoo's Nest* was published the same year as the Ontario Human Rights Code was passed, in 1962; and the novel depicts characters who are victims of a discriminatory society that is intolerant of people who cannot conform to socially prescribed roles and behavioural norms. Thus, the patients on Kesey's ward are victims of the "Combine" that works to assimilate people into their socially prescribed norms. However, even those who work to achieve the Combine's objective are revealed to be casualties of structural discrimination and abuse of power in the outside world. The trauma that Nurse Ratched and her orderlies have experienced in the outside world contextualize their cruel and dehumanizing treatment of patients within the ward. In 1964 Jean Rhys attempts to reconstruct Brontë's madwoman and tell her life-story in *Wide Sargasso Sea*. Her novel portrays how historical practices of patriarchy and ethnocentrism effectively disable women and others.

If the Reform phase of the institutional cycle opened with a victory for parents who were advocates for better services for their children, in and out of institutions (Parsons 5), the end of this phase demonstrates that family members cannot always be presumed to be the best judge of the capacity of a person with severe disabilities. Story and policy near the end of the Reform phase anticipate a more complex understanding of families in the final phase of the Cycle. Judith Krantz's wildly popular *Princess Daisy* (1980), and the real-life drama of *Clark v. Clark* (1982) depict the family as a sometimes empowering and, at other times, oppressive influence on the lives of people with mental disabilities.

## How Their Stories are Told

Berton's exposé is indicative of the beginning of a growing public awareness about the compromised quality of life for people with mental disabilities in Ontario. While outside expertise was commissioned to report on the status of the institutional system, the emphasis was still on the wisdom of government to determine how to realize a new objective of community integration for people who would once have been assigned to an institutional facility for most of their lives. At the same time, however, a more activist public was increasingly challenging the wisdom of government to address the social welfare issues that determined the rights and opportunities of citizens. Family members of people with mental disabilities,<sup>23</sup> and workers on the frontlines<sup>24</sup> became better organized and insisted on contributing to policy debate that affected the range and quality of services available to support people with mental disabilities.

As the wisdom of government institutions was increasingly challenged in society, so the legitimacy of cultural assumptions about what it means to be normal was questioned in the popular novel. In Ken Kesey's *One Flew Over the Cuckoo's Nest* Patrick McMurphy's story is narrated by a 'chronic' on the ward, named Bromden. Because Bromden is presumed to be deaf and dumb, he is given extraordinary access within the ward and insight regarding the motives of those who abuse the authority invested in them as healers and helpers. He explains that the custodial staff "don't bother

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<sup>23</sup> In 1971 the OAMR was composed of 117 locals in Ontario, and was a significant influence in the "development of appropriate legislation and suggested amendments to legislation when required to better meet the needs of the retarded" (Williston, 59).

<sup>24</sup> The Ontario Public Service Employees Union undertook independent consultations across the Province where family members, and disability professionals challenged the optimistic rhetoric of community living, and argued that the dismantlement of a Provincial system of institutional care put residents at significant risk in the wider community. See Marshall (1982).



not talking out loud about their hate secrets when I'm nearby because they think I'm deaf and dumb. Everybody thinks so. I'm cagey enough to fool them that much" (Kesey 3).

This access enhances Bromden's reliability as a narrator, despite his own illness that manifests itself in a perception of the institution as a diabolical machine: a Combine that detects fear and enforces submission.

Throughout the novel, Bromden is telling his own story as well as McMurphy's. He flashes back to increasingly vivid memories of his life before his hospitalization: A childhood spent fishing on ancient Aboriginal lands before the government flooded the Reserve and destroyed his community. In recalling his past, he realizes that he had begun to lose his voice before he even determined to give up speaking:

it wasn't me that started acting deaf; it was people that started acting like I was too dumb to hear or see or say anything at all...

...In the Army anybody with more stripes acted that way toward me. That was the way they figured you were supposed to act around someone looked like I did. And even as far back as grade school I can remember people saying that they didn't think I was listening, so they quit listening to the things I was saying. (Kesey 210)

As McMurphy's influence makes Bromden want to speak his mind to him, he increasingly struggles with his silence and the awareness that "I had to keep on acting deaf if I wanted to hear at all" (Kesey 209). For Bromden silence has been a sanctuary that keeps him safe from at least some of the cruelties perpetrated by others.

Bromden tells McMurphy's story several years after the time of their acquaintance. He explains to the reader how "I been silent so long now it's gonna roar out of me like floodwaters and you think the guy telling this is ranting and raving my

*God*; you think this is too horrible to have really happened, this is too awful to be the truth! But, please. It's still hard for me to have a clear mind thinking on it. But it's the truth even if it didn't happen" (Kesey 8). To the extent that characters with mental disabilities are able to speak for themselves, their versions of their life stories remind the reader that truth is perspectival. In other words, the behaviours of people diagnosed as crazy or incompetent may actually be an understandable response to trauma that they have experienced, trauma that may have precipitated the mental disability, or have been experienced as a result of abuse or exploitation because of the individual's impairment.

When Bromden finally speaks to McMurphy and tells him about the Combine, as well as the story of his life before he lost his voice and ended up on the ward, he concludes on the verge of despair because he just does not have the words to fully communicate his experience: "I can't say it all. It don't make sense." McMurphy makes an important distinction in his reply: "I didn't say it didn't make sense, Chief, I just said it was talkin' crazy." (Kesey 222) McMurphy is able to recognize truth in Bromden's metaphors. He realizes that, taken altogether, what Bromden recollects is a true account from his memory, even if no one else experiences the chemical fogs and whirling gears that give Bromden a language for theorizing the inhumanity of the asylum and its objectives.

Rhys' novel incorporates multiple voices to demonstrate how different perspectives on the same events communicate very different versions of the same story. In the first section of *Wide Sargasso Sea*, Antoinette Cosway gives her own first-person narrative of her life before becoming Bertha Rochester. However, her loss of authority to speak her own story is symbolized in the second section of the novel when Rochester assumes the role of narrator, immediately following their wedding. This shift in voice is

not explicitly indicated in the text. In fact, Rochester is not referred to by name at any point in the novel. The effect is to bestow upon the new husband the omniscience conventionally assigned to the third-person narrator. As her husband, Rochester has assumed authority over Antoinette's story from this point onward, to the extent that he even exercises the right to change her name to Bertha. The only explanation he gives for renaming his wife is that "it is a name I'm particularly fond of. I think of you as Bertha" (Rhys 86). The patriarchal tradition of women surrendering their name in marriage is, here, further enforced by Rochester indulging his inclination to reconstruct his wife's identity altogether by assigning her an English name.

Truth is provisional, determined by those who have the power to lend legitimacy to their narrative perspective. Having Antoinette literally lose her voice upon being transformed into Bertha Rochester emphasizes how disability is a social construction that is heavily influenced by patriarchal and colonizing traditions that have historically silenced women. As the second son of a father who does not wish to divide the family legacy, Rochester is briefly shown to struggle with his own duplicity in marrying a woman he does not love in order to secure his own interests. When he is honest with himself, he recognizes the elusiveness of an objective truth that can be relied upon: "suddenly, bewilderingly, I was certain that everything I had imagined to be truth was false. False. Only the magic and the dream are true-- all the rest's a lie" (Rhys 109). Nonetheless, with English law on his side, the version of the truth that he contrives is the one that prevails. By comparison, Antoinette's truth, even about her own life-story, has little worth.

A third version of Antoinette's story is told by her alleged half-brother, Daniel Cosway, in a letter to Rochester. The letter both accuses and condemns Antoinette,

despite the absence of any specific charge or evidence against the young woman (Rhys 57-60). Still, this testimony is enough to galvanize Rochester's unease in his marriage, and serves as his justification for abandoning any affection he may have been nurturing for his bride. When he eventually does question Antoinette about the letter's allegations, she asks him why he is so quick to believe a stranger's accusations without asking for her side, asserting that "[t]here is always the other side, always" (Rhys 81). This line alludes to a key theme of the novel, as a response to *Jane Eyre* and the story of Rochester's first wife who never gets to speak for herself.

The third section of the book opens with a monologue by Grace Poole, who is Bertha's keeper/caregiver in *Jane Eyre*, and silent in that novel. She speaks here to the pains taken by Rochester to control and contain the story of Mrs. Rochester. The existing household staff have been dismissed and Grace is offered double her salary if she can prevent the circulation of any "gossip" (Rhys 114) about the existence of Mrs. Rochester. Still, despite her confinement and the suppression of her very existence, Grace Poole also observes that Mrs Rochester "*hasn't lost her spirit. She's still fierce. I don't turn my back on her when her eyes have that look. I know it*" (Rhys 115). Grace Poole is an ambivalent figure in Brontë's original story and remains so here. She is not developed to an extent that the reader generates any definite sympathy or antipathy toward her. In *Wide Sargasso Sea*, Grace Poole gives her own perspective and speaks pragmatically about her role and her responsibility in a manner befitting someone who is well acquainted with the mentally disabled individual, as well as the world where she exists. That Grace Poole knows that the "look" in Bertha Rochester's eyes suggests that she too has felt fierce in her confinement. Perhaps every woman has.

Rhys finally concludes the novel by returning the narrative to Antoinette who anticipates her final exit. Like the parrot who perishes in the burning of her family home at Coulibri because Mr Mason had his wings clipped (Rhys 22); like the mother who succumbs to madness because she is not permitted to fly from her persecutors (as will be discussed below); Antoinette Bertha Cosway Rochester is also destined to go down in flames.

Much of disability policy debate revolves around the question of who is qualified to tell the story of the mad or retarded person. In Judith Krantz's novel the mentally disabled sister, Danielle Valensky, never speaks directly. The story is narrated in the third person, primarily from Daisy's point of view. Occasionally the motives and internal monologues of other characters are described, but Danielle exists only in terms of how she is perceived by others. She is always referred to in the third person and is important exclusively for her impact on her twin sister's life; an imperfect reflection of the beautiful, bright and successful other, but insubstantial in her own right. However, Krantz's storyline allows for enough intercourse between the two sisters before their separation to establish an attachment and a mutual understanding that transcends time and distance. This bond is represented in the childhood language that they share and is only understood between them (108-112), their mutual grief at Danielle's eventual removal to an institutional facility (122-123), and Daisy's enduring loyalty to her twin. In terms of the author's narrative purpose, it is essential that this bond exist in order to establish Daisy as a reliable advocate and protector of her sister's interests.

## **The Role of the Family**

This phase of the Institutional cycle opens with a journalist's public narrative about a personal experience:

On the last afternoon of 1959, I drove to Orillia with a friend of mine and his 12-year-old son. The boy is handsome, with large, dark eyes, but he is not very communicative for he will always have the mind of a child. He is retarded mentally. On holidays he comes home to his parents. The rest of the time he is a patient at the Ontario Hospital school.

There are 2,807 others like him, jammed together in facilities which would be heavily taxed if 1,000 patients were removed. More than 900 of them are hived in 70-year-old buildings. There is nowhere else for them to go. (Berton 31)<sup>25</sup>

The young boy being returned to the facility was the son of Jerry Anglin, then Institutions Chairman of the Ontario Association for the Mentally Retarded (Simmons, 1982, xv), which was an advocacy group founded by parents in 1953 and a forerunner of the Ontario Association for Community Living.

Although parents have always comprised the largest, most persistent advocacy group on behalf of people who cannot effectively advocate for themselves, Berton's column contributed to raising wider public awareness of a growing institutional crisis. The debate about the most appropriate response to what was increasingly perceived as a human rights issue must have been particularly troubling for these parents who for many years had been told that the institution was the best place for their children to get the care

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<sup>25</sup> Berton must have been given uncommon access for his tour, as Williston notes that in 1960 the hospital school "was truly a 'closed' institution and no parent was allowed beyond the front hall" (29).

and the training required to allow them to live as ‘normal’ a life as possible. Arguably, the most radical aspect of the Reform-era policy shift is the reversion of primary responsibility back to families as the most appropriate location for the care and training of people with mental disabilities. In his 1973 planning document, The Provincial Secretary for Social Development argued that,

[i]deally... the family of the retarded individual can provide him with the most familiar and most socially reassuring environment, with minimal additional costs imposed on the community. It does tend to place an extreme financial and emotional burden on the family, however, and it does not necessarily encourage the social development and adjustment of the retarded person. (Welch 12)

Many families were feeling pressure to assume roles and responsibilities that they had once been urged to relinquish. Furthermore, a family’s capacity to provide care would vary in relation to the financial resources at their disposal, the nature and extent of the individual’s mental impairments.

This confusion about family roles, as well as the personal and financial costs of care, are reflected in the literature of the time, and are discussed in this section. Some popular novels, such as Krantz’s *Princess Daisy*, still contrast the selfless caregiver and the bad parent in a fairly simplistic way. Increasingly, however, the Reform novel offers a more complex portrayal of the family struggling with personal issues and societal attitudes that challenge the ability to care for children, spouses and siblings with mental disabilities. In many cases the shift in emphasis from institutional to community care had a disproportionate impact on women as society’s primary caregivers, and compounded inequality between men and women in law and custom within patriarchal and colonizing cultures. This is the familial context that Rhys portrays in *Wide Sargasso Sea* where

patriarchal traditions in law and custom are also depicted as contributing to or exacerbating women's experiences of mental disability. In some cases, as in Kesey's novel, the family is peripheral to the action of the story. To the extent that it is referred to, it generally is portrayed as another of society's dysfunctional institutions. The ambiguous status of the family is made apparent in policy and novels of the Reform phase in the way it is sometimes identified as the source of mental disability, and at other times depicted as the most appropriate location for care.

In *Wide Sargasso Sea*, Antoinette recalls that part of her mother's motivation for marrying Mason had been to try to secure a passage for her disabled son, Pierre, so that he could obtain treatment that might cure his disability (17). Annette's despair is linked to her son's disability, as Antoinette recalls how, even though they had no money, "[s]he persuaded a Spanish Town doctor to visit my younger brother Pierre who staggered when he walked and couldn't speak distinctly. I don't know what the doctor told her or what she said to him but he never came again and after that she changed" (Rhys 4). Pierre's disability motivates the mother's ambition to leave a society already in the midst of social upheaval and retaliation against generations of racial oppression. In a society so sensitized to differences in class and physical appearance, Antoinette's mother is keenly sensitive to her son's vulnerability (16). Her inability to protect her family is a major contributing factor to Annette's complete and irreversible mental breakdown.

Both policy and popular novels identify the ability to meet the costs of care as essential for meeting extraordinary human need. However, in Krantz's novel, Danielle Valensky's story suggests that no amount of money is enough to ensure that parents have the personal capacity to support a child with severe mental disabilities. Daisy and Danielle Valensky are the offspring of a brief and passionate marriage between an



American actress, Francesca, and a Russian prince, Alexander (Stash) Valensky. When their twin daughters are born, one of the sisters is immediately identified as being mentally retarded. The father's reaction to this news is one of complete revulsion. In his attempt to console the father, the doctor who delivers the girls explains how

“[a]ccidents happen in nature, against which the utmost skill of man can do nothing except salvage as best it can.”

“*Salvage?*” Stash said the word as if he had never heard it before. What had he to do with salvage? There had never been any allowance in his life for loss, so what room could there be for salvage? (Krantz 69)

Stash Valensky's refusal to love his retarded daughter is explained as an outcome of being raised by a mother who was chronically ill. The boy's inability to save his mother from a slow death has made him intolerant of weakness of any kind:

From his earliest memories, the little boy, Alexander never knew what it was like to have a healthy mother. His babyish play with her was always cut short by someone who was afraid that he was tiring her. When Titiana read out loud to him, a nurse would always close the book far too soon. When Alexander grew old enough to play simple games of cards with his mother, her chief doctor took him aside and gravely warned him of the dangerous excitement engendered by any games of chance. His love for her was imprinted, from earliest memory, by the terrible tension which lies between the sick and the well. From babyhood on he was crippled, permanently, with a resentment, a wordless hatred, and a deep and irrationally superstitious fear of any sign of illness. (Krantz 38)

The father's capacity to love is disabled as a result of his childhood trauma. So intense is his aversion to disability of any kind that he manages to briefly convince his wife that the

child did not survive, and arranges to have Danielle fostered out to a woman who makes her living by caring for wealthy people's discarded children (Krantz 81).

Valensky's abandonment of his mentally disabled daughter speaks to the reality that not all parents are inclined to parent a disabled child (Landsman 111). According to Vanier, feelings of ambivalence and even aversion on the part of some parents towards offspring who are born with severe disabilities contribute to a reality where "those with intellectual disabilities are among the most oppressed and excluded people in the world. Even their own parents are frequently ashamed to have given birth to a child 'like that.' Such parents feel humiliated and ashamed by the apparent failure, so great is the social pressure to create a perfect baby" (72). As a result, some parents remove these children from their lives as the only way they can cope with their feelings of guilt or disappointment.

In contrast to the father who has no tolerance for imperfection, the good mother and sister of the Establishment phase are both recreated in Krantz's novel. When Francesca discovers that Danielle is not dead, she immediately reclaims her, leaves her marriage, and goes into exile with both daughters. She devotes her life to their care until she dies suddenly when the twins are six years old. The difference between the mother's and the father's response to their mentally disabled child is further contextualized by a medical model that was long established as the dominant framework for constructing disability by this time. The doctor who attends the births of Daisy and Danielle Valensky explains that

the mothers of retarded children often spend much less time with their normal children in favor of the sick one; yes, it was not at all impossible that the Princess would refuse to have the child institutionalized no matter how necessary it was.

Indeed, there were many such cases. The maternal instinct was often strengthened beyond the imagination of man by the care of a sick or retarded child and there was no force as strong as that instinct. Nature was indeed marvelous. Mothers were self-sacrificing. (Krantz 80)

Indeed, Francesca's love for her infant daughter is, if anything, intensified because of her total dependence. Danielle will always need her in ways that her twin sister will not.

Therefore,

it was with Dani that Francesca found her most peaceful and harmonious moments. Dani's eyes, like a baby's eyes, seemed to remember something of a previous life which couldn't be communicated, but which reassured and comforted her. Dani's vulnerability was her strength, since no one saw her without feeling the impulse to protect her. Dani was never unhappy because she was never frustrated. If she couldn't do something, she didn't bang furiously on the table the way Daisy did when she first discovered that she didn't know how to read. Dani didn't ask endless questions, didn't plague Francesca with demands to climb a tree, catch an earthworm, make cookies, train a hummingbird, take a walk in the woods and collect pebbles on the beach—all in the same breath, as Daisy did. (107)

Relationship with their parents, especially mother figures, is emphasized as paramount to the security of people with mental disabilities across all phases of the Institutional Cycle. In novels where these relationships are absent or dysfunctional the mentally disabled character is always extremely vulnerable.

In *Wide Sargasso Sea* it is implied that at least part of the explanation for Annette Mason's breakdown is her inability to save her disabled son, Pierre, from the attack on Coulibri. In Antoinette's version of her life-story she suggests that her mother cared

more for the younger brother, perhaps because he is so vulnerable: “she pushed me away, not roughly but calmly, coldly, without a word, as if she had decided once and for all that I was useless to her. She wanted to sit with Pierre or walk where she pleased without being pestered, she wanted peace and quiet. I was old enough to look after myself” (Rhys 5). The inability to prevent the disaster that she is able to foretell, and the loss of her child finally does push Annette over the edge into madness. Her mother’s decline into madness makes Antoinette vulnerable, in turn.

While nurturing capacity has been understood in popular literature and in policy as an innate feminine quality, Kesey satirizes this cultural assumption in *One Flew Over the Cuckoo’s Nest*. When McMurphy brings his fellow patients’ attention to the way Ratched manipulates and humiliates them in group therapy, Harding tells him, “[w]hy, see here, my friend Mr. McMurphy, my psychopathic sidekick, our Miss Ratched is a veritable angel of mercy and why just *everyone* knows it. She’s unselfish as the wind, toiling thanklessly for the good of all, day after day, five long days a week. That takes heart, my friend, heart” (61, emphasis in original). Ratched, of course, is no Mary Rudge or Susan Dixon. Instead, she rules her ward by a combination of degrading condescension, manipulative therapeutic tactics, drugs and, in extreme cases, shock therapy and radical surgery to ensure compliance to her authority.

If Ratched is woman who abuses her authority, Rhys writes about women who have no legitimate power at all within the family, and particularly within marriage. Antoinette loses her mother to a combination of patriarchal indifference and cultural prejudice that eventually breaks her spirit and her mind. Even while she still has her sanity, Antoinette’s mother is powerless to influence a course of action that would move her family out of harm’s way from the superstitions and local caste system that reviles

Annette and her progeny because she is the daughter of a slave owner and the widow of a slave owner. She marries to obtain security for herself and her children, but Annette is unable to convince her new husband of the danger they face in staying in the community. Antoinette recalls how her mother tried to impress upon her new husband the urgency of their need to leave Coulibri, but he would not listen. Instead, he told his wife that she was imagining an enmity that did not exist (Rhys 14). Thus, Rhys portrays how easily women's versions of their own life-story are dismissed or discredited even by those who are closest to them.

Annette's failure to have the veracity of her experience acknowledged has disastrous consequences: the family home is destroyed, her disabled son dies, and she loses her sanity as a result of her grief and helplessness. Having witnessed her mother's complete mental breakdown, Antoinette is understandably wary of entering into a marriage of her own. She is persuaded by Rochester, however, because she lives in a society where all women need to be attached to family, through blood or through marriage. Even Rochester, in his version of his wife's story, acknowledges Antoinette's reservations, which he sweeps away with romantic gallantry: "I kissed her fervently, promising her peace, happiness, safety" (Rhys 46). These three things are irrevocably lost to the bride by the time they leave for England. She has no resources, no friends, which is why she persists in seeing England as a beacon of hope if she can only get there (Rhys 68).

As the marriage deteriorates, Antoinette is urged by her childhood nursemaid, Christophine, to "[h]ave spunks and do battle for yourself. Speak to your husband calm and cool, tell him about your mother and all what happened in Coulibri and why she get sick and what they do to her. Don't bawl at the man and don't make crazy faces. Don't

cry either. Crying no good with him. Speak nice and make him understand''' (Rhys 72).

Before the madness overtakes her, Antoinette does try to tell her own version of her life story to her husband; and she tells Rochester, "[y]ou have no right... You have no right to ask questions about my mother and then refuse to listen to my answer" (Rhys 82).

However, social custom and policy empower him to overrule or dismiss his wife's version of the truth, to rename and renounce her without appeal to a higher justice.

As with her mother, Antoinette's fate is sealed when she fails to convince her husband to believe in her own account of her life-story. Instead, Rochester chooses to believe in unsubstantiated allegations against his wife and her family (Rhys 57-60) to justify removing her to England, and incarcerating her in his family estate. Rhys' version of Bertha Rochester's life narrative offers an explanation for the 'madwoman in the attic' that explores women's vulnerability to mental disability within the institution of marriage where policy and social custom invested all authority in the husband, with no appeal. Antoinette/Bertha's insanity is ultimately linked to her mother's (Rhys 107) and blamed on familial inheritance. This is the version of her story that is given and uncritically accepted in Brontë's *Jane Eyre*. However, Rhys is exploring alternative storylines that contribute to women's madness. She suggests in her version of Antoinette's story, before she is recast as Bertha, that her madness is an outcome of an abusive patriarchal system that invests men with power over women to break them down.

Antoinette does not have sufficient personal power or advocates to successfully challenge Rochester's construction of her. In the end, even Rochester acknowledges to himself the veracity of the accusation that is leveled against him by Christophine, who has cared for Antoinette since childhood. Christophine tells Rochester he has only pretended to believe unsubstantiated allegations about Antoinette as an excuse to extricate

himself from his wife (Rhys 99). In their final exchange, Christophine tells him that madness is a diagnosis of convenience bestowed by men with power on people without. She asks, “[y]ou think you fool me? You want her money but you don’t want her. It is in your mind to pretend she is mad. I know it. The doctors say what you tell them to say” (Rhys 104). Christophine’s version of Antoinette’s story transfers responsibility for her madness from the woman he has renamed Bertha, and her family to him. Rochester is the one responsible for breaking up his wife (99).

In *One Flew Over the Cuckoo’s Nest*, Nurse Ratched reiterates the popular assumption that blames parents for their children’s mental disability, legitimizing this perspective through her authority as a psychiatric nurse. When introducing a punishment to the patients on the ward for defying her authority by boycotting their housekeeping duties, she explains the therapeutic rationalization for her revenge:

“Please understand: We do not impose certain rules and restrictions on you without a great deal of thought about their therapeutic value. A good many of you are in here because you could not adjust to the rules of society in the Outside World, because you refused to face up to them, because you tried to circumvent and avoid them. At some time—perhaps in your childhood—you may have been allowed to get away with flouting the rules of society. When you broke a rule you knew it. You wanted to be dealt with, *needed* it, but the punishment did not come. That foolish lenience on the part of your parents may have been the germ that grew into your present illness.” (Kesey 199-200)

This is not just meanness on Ratched’s part. Kesey is pointing to dominant medical approaches to mental disability that essentially blamed parents for a wide range of diagnoses and deviant behaviours. This is consistent with perspectives depicted in other

novels written in the Reform period, which reflect the influence of therapeutic approaches emphasizing family dysfunction as a dominant cause of mental illness.<sup>26</sup> Such views had long been held, but had only recently come under critical scrutiny. As the case for de-institutionalization began to evolve, policy makers, social workers and other human services professionals struggled to reconcile how families could not be both the problem and the solution in the life stories of people with mental disabilities.

*One Flew Over the Cuckoo's Nest* presents a cast of characters whose family relationships are represented as broken, dysfunctional, or nonexistent. Indeed, it is hard to conceive how the abuses perpetrated on the ward could occur in the face of active interest from family members, or other advocates on the Outside. The only references to family connections that are a source of strength, or at least consolation, are the reminiscences that are offered by the story's narrator, Chief Bromden. He survives and escapes the asylum partly on the strength of his memories of his past, which his relationship with McMurphy help him to recall. When McMurphy walks into the ward, Bromden observes that

[h]e talks a little the way Papa used to, voice loud and full of hell, but he doesn't look like Papa; Papa was a full-blood Columbia Indian—a chief—and hard and shiny as a gunstock. This guy is redheaded with long red sideburns and a tangle of curls out from under his cap, been needing cut for a long time, and he's broad as Papa was tall, broad across the jaw and shoulders and chest, a broad white devilish grin, and he's hard in a different kind of way from Papa, kind of the way a baseball

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<sup>26</sup> For example, in Joanne Greenberg's (1964) *I Never Promised You a Rose Garden* Dr. Fried, the protagonist's psychiatrist observes that, "[m]any parents said—even thought—that they wanted help for their children, only to show, subtly or directly, that their children were part of a secret shame for their own ruin" (27).



is hard under the scuffed leather. (Kesey 12-13)

The comparison to Bromden's father that Murphy inspires is significant because McMurphy does represent a kind of parental figure to the other patients on the ward. They rely on his strength and his advocacy, as children rely on their parents.

The ambivalence about the role of the family in the lives of people with mental disabilities is also reflected in a policy that did not encourage participation in their relatives' lives within the institution. In his report, Williston notes that, in Ontario the institution was often "hundreds of miles from the patient's home. Hence, visits from the family are both expensive and time-consuming. They tend to become infrequent... Contacts between the retarded person and his family are weakened and often lost altogether" (65). As a result, it was not unusual for people with chronic mental disabilities to become estranged from their families. In this respect Daisy and Danielle Valensky's relationship, in *Princess Daisy*, is atypical. Somehow, the sisters maintain their relationship. Even when Daisy moves from England to America, through letters, pictures and photographs that Daisy sends she is able to maintain her presence in her sister's life.

The high quality care that keeps Danielle Valensky safe and happy in her institutional school does not come cheap. So, when their parents die and Daisy's inheritance is lost, Daisy struggles to earn enough money to maintain her sister in the facility that she knows as home (Krantz 223). Even if the quality of care that Danielle receives was available to all families, most could not afford it. In other cases people may make poor choices on behalf of others as a result of ingrained prejudice, guilt, personal trauma, or indifference.

In extreme circumstances, the courts have been called upon to arbitrate what is the most just course of action in the interests of people with severe disabilities. This happened in Ontario, in 1982, when Matthew Justin Clark appealed to the courts for the right to emancipate himself from his parents' guardianship. His parents were opposing Mr. Clark's decision to reside outside of the Rideau Residential facility, even though they had maintained no relationship with their son since his placement at the age of two. This twenty-year-old man's disabilities included severe physical impairments from cerebral palsy, as well as mental retardation determined to be in the mild to moderate range (Clark v. Clark, para. 21). He also could not speak. He communicated his case through Blissymbolics,<sup>27</sup> and it was supported through the testimony of doctors and frontline workers who had known Mr. Clark for many years. Judge John Matheson pronounced his verdict in favour of Justin Clark "in language which clearly affirmed Justin's full humanity" (Rioux & Frazee 182). The judgment validated the legitimacy of Justin Clark's personal narrative, despite his significant mental impairments.

This decision challenged the generally accepted notion that family members always are always best equipped to determine the best interests of an individual with a severe mental disability. Instead, Judge Matheson emphasized the principle of individual rights, which should not preclude the right of individuals to take risks:

Sir William Blackstone in Book the First of Commentaries on the Laws of England stated in 1809 that the principle aim of society is to guard and protect individuals in the proper exercise of their individual rights. Such rights he

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<sup>27</sup> Blissymbolics refers to a type of communication program that utilizes pictorial symbols to allow some people who are nonverbal to respond to questions and express themselves. Justin Clark "was the first person in Canada ever to give legal evidence using this means of communication" (Rioux & Frazee 181-182).

characterized as absolute. I believe a courageous man such as Justin Clark is entitled to take a risk.

With incredible effort Justin Clark has managed to communicate his passion for freedom as well as his love of family during the course of this trial.

I have accepted that and believe that to be so...

We have, all of us, recognized a gentle, trusting, believing spirit and very much a thinking human being who has his unique part to play in our compassionate interdependent society. ...

I find and I declare Matthew Justin Clark to be mentally competent. (Clark v. Clark, para. 41-45)

Judgments on the capacity of people with mental disabilities to self-advocate have typically relied heavily on the authority of medical models and, more recently, the perspectives of parents. However, no expertise should be uncritically accepted when its implementation may undermine fundamental human rights.

As Section 15 of the Charter of Rights and Freedoms (1982) specifically affirmed the equality rights of people with mental and physical disabilities in law (Rioux & Frazee 171), a rhetoric of community living continued to evolve. Policy planners were taxed with the responsibility for building community capacity to support people being diverted from the institutional system. This objective included determining how to support families that undertake to provide care for family members who would once have been institutionalized as a matter of course. In his 1971 report, Williston argued that it is incumbent upon families to take an active role in supporting their children with mental disabilities, but he also insisted that they cannot be expected to do it alone.

There is a need for acceptance of the idea that the responsibility of a community to

help parents of handicapped children to bring up their children involves the providing of a totality of services. This concept is widely accepted in such fields as education, medicine, health, baby bonuses, old age pensions and Thalidomide children. In providing social care for handicapped children and their families (historically administered as an adjunct to the poor law), public concern has not until very recently been developed to the same extent. I suggest that we must soon spell the death knell on our poor law legacy as applied to handicapped persons and to the social attitudes and practices which stem from them. (73)

The stories told in the Reform era suggest that the prospects for people with mental disabilities varied, depending upon the extent that families were actively engaged in their lives, and the resources available to them. These include financial resources to purchase services and supports, as well as the extent of personal attributes and knowledge to be effective advocates for community support. Without the seclusion that the institution provides, families also have to be able to nurture self-esteem in their children to help them confront the discrimination that they will face in the community.

### **Community Responsibility**

Berton's revelations about the crisis in care at Orillia were published as a period of political activism was beginning to mobilize many marginalized populations, including women, racial and cultural minority populations. A growing civil rights movement culminated in the

flowerchild 60s [when] conservative old Ontario decided to become progressive. Just as it had opted to revolutionize its school system... it espoused the scientifically-sound and morally-humane idea of releasing the mentally

handicapped and ill from the Dickensian chill of the custodial institutions into the warm and caring community. (Marshall 7)

Marshall is being somewhat facetious here, as the capacity of the community to care for people with mental disabilities has been hotly debated in response to the enthusiastic rhetoric of community living. Still, the 1960s were optimistic times for many people: more inclusive views about human rights, generally, together with the human potential of people with mental disabilities converged with a pressing political need to contain the costs of institutional sprawl in Ontario. However, these emerging perspectives could not easily overcome generations of fear and stigma associated with disability, nurtured by a social policy context that had long promoted segregation as the best option for individuals with mental disabilities, their families, and society.

Jean Vanier believes that “[w]hen we ally ourselves with the excluded in society, not only are we enabled to see people as people and join them in their struggle for justice, to work for community and places of belonging, but we also develop the critical tools for seeing what is wrong in our own society” (96). In a similar way, novelists have used disability as a device for making larger statements about social justice. In this phase of the Institutional Cycle, Kesey and Rhys both draw attention to how the community disables individuals and groups through discriminatory attitudes about gender and race, as well as mental diversity. At the same time, policy makes its own assumptions about the abilities and needs of a diverse population, as well as the communities where they live. In a society that is beginning to undertake a policy of community integration of people with mental disabilities, those who look normal and are perceived as eternal children are most likely to elicit public support. However, Krantz’s novel suggests that even these

sympathetic characters are often still perceived as most happy and secure living apart from mainstream society.<sup>28</sup>

The mental hospital in *One Flew Over the Cuckoo's Nest* ostensibly exists to help people adjust to normal functioning in society.<sup>29</sup> In the “Therapeutic Community” that is practised in the group sessions on the ward, the ward psychiatrist explains “how a guy has to learn to get along in a group before he’ll be able to function in normal society; how the group can help the guy by showing him where he’s out of place; how society is what decides who’s sane and who isn’t, so you got to measure up” (Kesey 49). Despite its theoretical claims, however, the Therapeutic Community is actually a tool of coercion. Its purpose is to keep the focus of deviance on the individual, without questioning the prejudices and the abuses that have been perpetrated on the Outside. This, in turn, works to diminish self-esteem, as well as to exacerbate and even create mental disability.

The importance of passing as normal<sup>30</sup> is portrayed in Kesey’s novel when McMurphy succeeds in obtaining permission for himself and nine other patients to leave the ward to go out on a fishing charter. Initially giddy in their courage to sign up for the expedition, despite Ratched’s intimidation tactics (227), they suffer from the reactions of people on the Outside who realize where they are from:

It was a fine woodsmoked autumn day, full of the sound of kids punting footballs

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<sup>28</sup> The literature review undertaken failed to find one popular or critically acclaimed novel from this period that depicted a positive outcome for a person with a mental disability living in the community. Greenberg’s (1964) *I Never Promised You a Rose Garden* also depicts the mental asylum as a sometimes abusive facility that still functions as a necessary asylum from society and the family, which are depicted as systems that exacerbate mental disability. Similarly, Timothy Findley’s (1967) *The Last of the Crazy People*, portrays a family struggling with different manifestations of mental disability as isolated from the wider community.

<sup>29</sup> As explained in chapter three, a functional model of disability theory emphasizes training people with mental disabilities to accommodate their impairments and any associated behaviours to the norms of mainstream society (Roeher Institute 15).

<sup>30</sup> Michalko explains why it is important for people with disabilities to look and behave like normal people in order to gain social acceptance. He explains: “My goal in passing was to demonstrate that I was worthy of the privilege that came from being ‘normal’” (149).

and the putter of small airplanes, and everybody should've been happy just being outside in it. But we all stood in a silent bunch with our hands in our pockets while the doctor walked to get his car. A silent bunch, watching the townspeople who were driving past on their way to work slow down to gawk at all the loonies in their green uniforms. (Kesey 234)

The self-consciousness that the patients feel at the outset sinks further into humiliation when the cars stop at a nearby gas station to fill up. When the gas station attendants attempt to exploit their status as asylum patients being passed off as a work crew by their attending physician, Bromden observes: "I could see everybody was feeling pretty bad. The doctor's lying made us feel worse than ever—not because of the lie, so much, but because of the truth" (Kesey 235-236). These men have been institutionalized so long that they cannot succeed at integrating into the wider community without exposing themselves to the negative judgment and discriminatory treatment from others.

Realizing this, McMurphy draws upon the fear that people have of mental disability and its associations with violence. By exploiting the stereotype of the violent madman he recasts his travel companions:

"Now, Hank, don't you see that was just a kindly precaution to keep from *startlin'* you folks with the truth? The doc wouldn't lie like that about just *any* patients, but we ain't ordinary nuts; we're every bloody one of us hot off the criminal-insane ward, on our way to San Quentin where they got better facilities to handle us. You see that freckle-faced kid there? Now he might look like he's right off a *Saturday Evening Post* cover, but he's an insane knife artist that killed three men. The man beside him is known as the Bull Goose Loony, unpredictable as a wild hog. You see that big guy? He's an Indian and he beat six white men to death with a pick

handle when they tried to cheat him trading muskrat hides.” (Kesey 236-237 emphasis in original)

In fact, the number of people with mental disabilities who have violent propensities is very small (Williston 7). However, when the cars pull away having only paid government rate for their gas and supplies, all the patients have gained confidence. Harding, in particular, realizes for the first time how ““mental illness could have the aspect of power, *power*”” (238) when the subjects of societal stereotypes are able to take control of them.

McMurphy helps empower his fellow patients to reconstruct their stories by exploiting a stereotype of the madman, whereas in Rhys’ novel, *Wide Sargasso Sea*, the transformation of Antoinette into Bertha represents the limitations of that kind of power, especially for women. Written as a prequel to Brontë’s *Jane Eyre*, Rhys attempts to tell the story of Bertha Cosway/Mason’s life, from the period before she was Edward Rochester’s wife, indeed before she was Bertha. It is, at least in part, a response to what Rhys perceived as Brontë’s cultural imperialism (Jenkins xi), and the incomplete construction of the original Mrs. Rochester (Jenkins vii). Post-colonial critics have argued that “Bertha Rochester as a West Indian ‘Creole’, whether of white or mixed race, is demonized [in *Jane Eyre*] by a racist ideology... In such readings, the treatment of Rochester’s first wife as an amoral maniac of degenerate race intimates a queasy racism which pollutes the ethic of the novel” (Davies xiii). In Brontë’s original depiction of Bertha Rochester it is difficult to tell from Jane’s description to what extent Bertha’s bloated, distorted features are shaped by madness or ethnicity. There does seem to be a deliberate blurring of these aspects of physical complexion in Jane’s description of an apparition with features that were “[f]earful and ghastly to me... I never saw a face like



it! It was a discoloured face—it was a savage face. I wish I could forget the roll of the red eyes and the fearful blackened inflation of the lineaments!” (Brontë 327). Jane continues to refer to Bertha as an object by explaining to Rochester that “[t]his, sir, was purple: the lips were swelled and dark; the brow furrowed: the black eyebrows widely raised over the bloodshot eyes”(Brontë 327). The inference is that the madwoman is a creature not only outside of the beholder’s English race or ethnicity, but also foreign enough to be outside the human species.

Rhys’ version of Antoinette/Bertha Cosway’s story picks up on this racial ambiguity in her first person narrative. In the first part of *Wide Sargasso Sea*, Antoinette speaks to how the prejudice and social isolation that her family suffers, within the community she was born into, is inflected with racism. The opening lines of the novel identify Antoinette and her family as marginalized within their own community:

They say when trouble comes close ranks, and so the white people did. But we were not of their ranks. The Jamaican ladies had never approved of my mother, ‘because she pretty like pretty self’ Christophine said.

She was my father’s second wife, far too young for him they thought, and, worse still, a Martinique girl. (Rhys 3)

The emancipation of slaves upsets the social order in Coulibri and contributes to the vulnerability of Antoinette and her family as former slave owners. Antoinette recalls: “I never looked at any strange negro. They hated us. They called us white cockroaches. Let sleeping curs lie. One day a little girl followed me singing, ‘Go away white cockroach, go away, go away.’ I walked fast, but she walked faster. ‘White cockroach, go away, go away. Nobody want you. Go away’” (Rhys 7). Antoinette’s mother, Annette, rallies to attract and marry an Englishman, Mr. Mason. She tries in vain to

convince him of their peril at Coulibri and pleads with him to remove them from the community and its enmity toward them, but he will not believe her (Rhys 14-16).

The toll that her family's social isolation takes on Antoinette's mother eventually reaches a crisis when their home is burned down by vengeful negroes, killing Antoinette's disabled younger brother, Pierre: "she began to scream abuse at Mr Mason, calling him a fool, a cruel stupid fool. 'I told you,' she said, 'I told you what would happen again and again.' Her voice broke, but still she screamed, 'You would not listen, you sneered at me, you grinning hypocrite, you ought not to live either, you know so much, don't you?'" (Rhys 20). Grief and loss destroys her mother's sanity, and she is reduced to the madwoman the community had already determined her to be. These traumas that Antoinette suffers in childhood may be read as contributing to her own eventual mental collapse, after her husband refuses to believe in her version of her life narrative and she has no one to support or advocate for her.

Kesey's novel also demonstrates how people who are discriminated against in society will internalize those attitudes and behaviours and, in turn, persecute individuals who are even more marginalized. In *One Flew Over the Cuckoo's Nest*, Ratched exploits the rage and humiliation of her hand-picked orderlies to persecute her charges on the ward. She recruits her workers by appealing to the hatred these African American men have accumulated through their experiences of a lifetime of discrimination and violence in the outside world. Bromden explains how Ratched's first recruit learned hate by watching his mother being raped:

his papa stood by tied to the hot iron stove with plow traces, blood streaming into his shoes. The boy watched from a closet five years old and squinting his eye to peep out the crack between the door and the jamb, and he never grew an inch

after... Eyelids like thin gray leather, he lifts them up just a bit whenever a new white man comes on the ward, peeks out from under them and studies the man up and down and nods just once like he's oh yes made positive certain of something he was already sure of. He wanted to carry a sock full of birdshot when he first came on the job, to work the patients into shape, but [Ratched] told him they didn't do it that way anymore, made him leave the sap at home and taught him her own technique; taught him not to show his hate and to be calm and wait, wait for a little advantage, a little slack, then twist the rope and keep the pressure steady. All the time. That's the way you get them into shape, she taught him. (Kesey 30)

Like the patients they terrorize, Ratched's orderlies are refugees from the outside world: the place where identities are constructed, power is designated and abused. In the ward, the oppressed ascend, but are every bit as tyrannical.<sup>31</sup>

Bromden's own life story is shaped by structural discrimination and injustice. He compares McMurphy's calculated decision to at least pretend to defer to ward authority with his own father's submission to government agents who paid off the people of his Aboriginal nation in order to build a dam and flood their reservation: "Papa had done the smart thing signing the papers; there wasn't anything to gain by bucking it. The government would of got it anyhow, sooner or later; this way the tribe would get paid good. It was the smart thing. McMurphy was doing the smart thing. I could see that. He was giving in because it was the smartest thing to do" (Kesey 174). In his experience, bureaucrats are oblivious in the face of objection. They never heard Bromden or his

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<sup>31</sup> In *Disturbing the Peace* (1975), Richard Yates depicts a ward for violent men in the famous Bellevue mental hospital, in 1960. Again, all the frontline staff are black men. One of the patients explains that the reason that the administration only hires "spades" is "'because no white man'd *work* here for the kind of money they get'" (31).

father when they tried to explain a different point of view: “the apparatus inside them take the words... I just said and try to fit the words in here and there, this place and that, and when they find the words don’t have any place ready-made where they’ll fit, the machinery disposes of the words like they weren’t even spoken” (Kesey 213). This demonstrates a cynical approach to consultation and policy planning where government bureaucrats go through the motions of consultation only to either manipulate or ignore perspectives that are inconsistent with a predetermined course of action.<sup>32</sup>

The cultural prejudice that Rhys perceives as being associated with the original creation of Bertha is further extended to the oppression of women in a patriarchal culture that has existed since the Bible. This is apparent in the way that Antoinette’s home is associated with the Garden of Eden. Antoinette recalls:

Our garden was large and beautiful as that garden in the Bible—the tree of life grew there. But it had gone wild. The paths were overgrown and the smell of dead flowers mixed with the fresh living smell. Underneath the tree ferns, tall as forest tree ferns, the light was green. Orchids flourished out of reach or for some reason not to be touched. One was snaky looking, another like an octopus with long thin brown tentacles bare of leaves hanging from a twisted root. (4)

While the idiot tends to be associated with nature in ways that emphasize the character’s innocence, the explicit reference here to the Garden of Eden also alludes to Original Sin. Women are marked in Genesis as especially linked with sin; and madness, particularly in

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<sup>32</sup> Gambrill (2001) criticizes the social work profession, specifically, for failing to undertake or ignoring the findings of evidence-based research, including the informed perspectives of service users, that may undermine its status as a profession that provides “special expertise to address certain kinds of problems” (166).

women, has also been regularly been linked in Western culture to sinful deviance (Gilbert & Gubar 3).

Given the turbulence and tragedy of her childhood, Antoinette enters her marriage aware of her personal vulnerability. She hardly knows the man who is to be her protector, therefore, it is hardly surprising that she cannot trust the happiness that she feels in the first weeks of their honeymoon. She asks Rochester:

‘Why did you make me want to live? Why did you do that to me?’

‘Because I wished it. Isn’t that enough?’

‘Yes, it is enough. But if one day you didn’t wish it. What should I do then? Suppose you took this happiness away when I wasn’t looking...’

‘And lose my own? Who’d be so foolish?’

‘I am not used to happiness,’ she said. ‘It makes me afraid.’ (Rhys 55)

The romantic rituals of English courtship are social conventions; motions that the groom goes through, perhaps hoping that in participating in those rituals he can make them be true. However, at least with himself Rochester is very honest: “I did not love her” (Rhys 56). As a result, Antoinette’s difficulty with trusting in her husband’s endearments is actually insightful.

Still, Antoinette does initially enjoy a degree of security in her marriage. While Rochester is at least physically attracted to his bride, he perceives her to be “not a stupid child but as an obstinate one” (Rhys 56). Although there are hints suggesting a predisposition for mental disability (Rhys 52), Antoinette retains Rochester’s goodwill as long as she maintains her beauty and a kind of childish innocence that predisposes her husband to be indulgent. Antoinette’s transformation occurs after Rochester renames her Bertha. It is complete after he communicates the withdrawal of his affections by having a

sexual encounter with a housemaid within earshot of his wife, on the other side of her bedroom door (Rhys 89-90). The next time he sees his wife, her “hair hung uncombed and dull into her eyes which were inflamed and staring, her face was very flushed and looked swollen... when she spoke her voice was low, almost inaudible” (Rhys 94). At this point Antoinette has completely lost her voice and the ability to elicit any sympathy or support from any quarter is lost.

Interestingly, once Rochester’s conquest over his wife is complete, he reverts back to referring to her in childish endearments. In contemplating their departure for England, he considers that,

[i]f she... weeps, I’ll take her in my arms, my lunatic. She’s mad but *mine, mine*.

What will I care for gods or devils or Fate itself. If she smiles

or weeps or both. *For me*.

Antoinetta—I can be gentle too. Hide your face. Hide yourself but in my arms. You’ll soon see how gentle. My lunatic. My mad girl. (Rhys 108, emphasis in original)

Antoinette’s fate is sealed when she departs without any word or expression of remorse. Because she does not behave in ways that elicit any sympathy for her mental incapacity, she receives none.

Rhys’ story about the transformation of Antoinette Cosway into Bertha Rochester, the madwoman in the attic, contrasts with Krantz’s presentation of a character whose claim to protection is assured because she does not transform from the eternal child into a depraved woman. In her novel, Krantz wants to make both sisters sympathetic characters. To that end, the doctor attending their birth is anxious to assure the parents that in spite of their daughter’s retardation, Danielle “will look normal”

(Krantz 88). When Francesca is re-united with the disabled daughter whom she has been made to believe is dead, she scrutinizes Danielle and considers

How small she was. How incredibly sweet. Silver blonde hair, curly and fine. A grave face, a bit sad, but so marvelously familiar. And the eyes—the same velvety black, the black of a purple pansy, Daisy’s eyes. But dull. Just a little dull.<sup>33</sup>

Perhaps only dull if you compared her to Daisy... and that was something you must never, never do, never again. (Krantz 91-92)

Well into adulthood it is apparent that Danielle’s physical appearance reflects the limited intellectual development that she has attained. When the adult Daisy reflects upon her most recent reunion with her sister she observes to herself that “Dani had not changed, had remained, eerily beautiful and untouched by time, a happy five-year old in Daisy’s body” (Krantz 389). Emphasizing what is attractive, child-like or endearing about a person with mental disabilities contributes to generating sympathy for these individuals, and generating advocacy on their behalf.

For example, it is significant that the description of the young boy in Berton’s column draws attention to both his physical attractiveness as well as his communication impairments. He looks normal, but he is vulnerable and “will always have the mind of a child” (Berton 31). In this way, Berton creates a subject who evokes the reader’s

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<sup>33</sup> Such imagery recalls recurring descriptions in Establishment novels that identify idiocy in the eyes of the disabled character. In *Barnaby Rudge*, Dickens describes his idiot-hero as having “a glassy luster of his large protruding eyes” (Dickens 35). Gaskell’s, Willie Dixon has “restless eyes and ever-open mouth” (21). In Brontë’s *Jane Eyre*, the eyes are especially important indicators of character. When Rochester emphasizes the contrast between his mad wife and Jane, he invites his witnesses to “[c]ompare these clear eyes with the red balls yonder” (339). Bertha’s brother, Mason, has an eye that is described as “large and well cut, but the life looking out of it was a tame, vacant life... His eye wandered, and had no meaning in its wandering (220-221). In contrast, when Jane draws Rochester’s portrait, she leaves the eyes for last “because they required the most careful working. I drew them large; I shaped them well: the eyelashes I traced long and somber; the irids lustrous and large. ‘Good! But not quite the thing,’ I thought, as I surveyed the effect: ‘they want more force and spirit;’ and I wrought the shades blacker, that the light might flash more brilliantly” (Brontë 269).

compassion. In *Princess Daisy*, this construction of Danielle as an eternal child legitimizes her claim for care and protection within the institution, for the duration of her life. Of course, such attitudes also contribute to the infantilization of people with mental disabilities and the diminishment of their right to exercise personal autonomy.

Furthermore, in a novel that focuses on the ambitions of characters belonging to a society preoccupied with beauty, glamour and wealth, *Princess Daisy* does not take a critical stance in relation to these values. When the existence of Daisy's secret twin is revealed in *People* magazine, the reaction from the publicity team of the agency where Daisy is under contract seems to validate Daisy's motives for protecting Danielle from public exposure:

"Her features are different, no, not *different* really, but just not quite as... clear, not as fine. She looks, oh, younger, as if she doesn't have a sense of humour," Jenny said wonderingly. "But it *is* the same face... Daisy's face."

"No!" Candice said. "Not the *same*—you wouldn't look *twice* at her!..."

Neither woman could take her eyes off the haunting picture of the twins. They were unable to stop comparing the slight but all-important differences in their faces which made of one a glorious beauty and the other unformed, unfinished, uninteresting, with a muted little smile, pathos in her big black eyes. (Krantz 433-434, emphasis in original).

When Danielle's existence is exposed, so is society's antipathy for the visible features of her mental disability. The differences in their faces that are described as "slight but all-important" because they are significant enough to separate Danielle from mainstream society as someone who is "unformed, unfinished, uninteresting". Daisy eventually reconciles herself to this unauthorized exposé, and even experiences a sense of liberty as



a result of being unburdened by the secret of her sister. However, Danielle's presentation in the novel never really challenges the reaction to the photograph because, as a character, she is essentially unformed and uninteresting.

The Reform literary sample suggests that anybody with personal attachments, behaviours or habits that deviate from the prescribed cultural norm are vulnerable to social persecution and becoming disabled for their difference. By the end of *One Flew Over the Cuckoo's Nest*, Harding realizes that this is what had happened to him. When McMurphy asks him how he ended up on the ward and staying so long Harding answers:

"I could give you Freudian reasons with fancy talk, and that would be right as far as it went. But what you want are the reasons for the reasons, and I'm not able to give you those. Not for the others, anyway. For myself? Guilt. Shame. Fear. Self-belittlement. I discovered at an early age that I was—shall we be kind and say different? It's a better, more general word than the other one. I indulged in certain practices that our society regards as shameful. And I got sick. It wasn't the practices, I don't think, it was the feeling that the great, deadly, pointing forefinger of society was pointing at me—and the great voice of millions chanting, 'Shame. Shame. Shame.' It's society's way of dealing with someone different." (Kesey 307-308)

During the Reform period, homosexuality was still predominantly constructed as a disease that could be treated and cured (Szasz 166-168).

However, Kesey does finally try to suggest that everyone involved in the mental health system is inevitably a victim or servant of the Combine: Bromden's metaphor of the machine that works to assimilate people into their prescribed roles in society. When McMurphy and Bromden are sent to the Disturbed Ward, following their fight with the

orderlies, they have their injuries treated. Bromden's recollection of the sympathetic care that they receive from the nurse on this ward re-asserts the ideal of the nurse as healer:

the nurse—about as big as the small end of nothing whittled to a fine point, as  
McMurphy put it later—undid our cuffs and gave McMurphy a cigarette and gave  
me a stick of gum. She said she remembered that I chewed gum. I didn't  
remember her at all. McMurphy smoked while she dipped her little hand full of  
pink birthday candles into a jar of salve and worked over his cuts, flinching every  
time he flinched and telling him she was sorry. She picked up one of his hands in  
both of hers and turned it over and salved his knuckles. "Who was it?" she asked,  
looking at the knuckles. "Was it Washington or Warren?" (Kesey 278)

When McMurphy explains how he fought to prevent an assault against another patient, the nurse "nodded and looked at her feet. 'It's not all like her ward,' she said. 'A lot of it is, but not all. Army nurses, trying to run an Army hospital. They are a little sick themselves'" (Kesey 278). This scene also finally offers a human explanation for Ratched's ruthless need to control the ward as a symptom of her own trauma suffered on the Outside.

As the patients on the ward grow in their own self-assurance, they are able to contribute insight into how the abuses in the ward are allowed to occur. Scanlon, for example, suggests that the general public is complicit in tolerating the methods of the hospital. When McMurphy first gets educated about EST and lobotomy by the others on the ward he asks why the public doesn't object to such practices.<sup>34</sup> "I don't think you

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<sup>34</sup> In his study of mental health practices and policy in Ontario, Simmons finds that although lobotomy and other radical treatments like insulin coma were once regularly and indiscriminately prescribed to mental patients, by the 1960s such procedures were already very rarely performed in Canada, and never without

fully understand the public, my friend; in this country, when something is out of order, then the quickest way to get it fixed is the best way” (Kesey 190). Scanlon implies that perhaps the public does not necessarily want to know what goes on within the walls of its mental wards and institutions.<sup>35</sup> Ratched rules with society’s implicit consent, and “[g]etting rid of her wouldn’t be getting shut of the real deep-down hang-up that’s causing the gripes” (Kesey 192) on the ward. In other words, Ratched is not the problem, she only an instrument of society’s will to enforce conformity and assimilate difference.

Berton also suggests, in his column, that the public’s willful ignorance made the substandard living conditions in Ontario’s largest institution possible. With the social misfits out of sight, they are also out of mind. He concludes that:

Orillia’s real problem is public neglect. It is easier to appropriate funds for spectacular public projects such as highways and airports than for living space for tiny tots with clouded minds. Do not blame the present Department of Health for Orillia’s conditions. Blame yourself.

Remember this: After Hitler fell, and the horrors of the slave camps were exposed, many Germans excused themselves because they said they did not know what went on behind those walls; no one had told them. Well, you have been told about Orillia. (31)

In fact, the public response generated by this column embarrassed the Provincial government into finding the resources to speed up some renovations at Orillia, and the

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consent. By the 1970s they were banned altogether in this province. Between 1944 and 1967, approximately 1000 lobotomies were done at the various provincial mental hospitals (1990, 209-210).

<sup>35</sup> Debate about consent, involuntary treatment and controversial therapeutic techniques such as EST are addressed in ch. 4 of the Kirby Commission’s report.

development of more institutional spaces across the province to address overcrowding issues. However, Williston's report indicates that most of the concerns raised by Berton had not been meaningfully addressed eleven years later. Instead, he found that, "[t]his hospital school is located on six hundred beautiful acres. Most of the buildings, however, are old and antiquated. Two in particular constitute a very serious fire hazard. There should be an immediate investigation by a fire marshall. There is serious overcrowding... There is a very serious shortage of professional staff" (36). What becomes apparent is how, even when policy action is demanded in terms of a fundamental human rights crisis, political bureaucracies move slowly. This policy context, together with public apathy, allowed for the entrenchment of deplorable living conditions for some of society's most marginalized members to be sustained for so long.

In the end, despite the demise of McMurphy, *Ratched's* authority is diminished; and most of the others have gained enough self-esteem to attempt life again on the Outside. Yet, in the final pages of the story, the reader is reminded that struggles for justice and equality are battles that are never won outright. In his final lucid moments, as the end of his own fight was approaching, McMurphy "was in his chair in the corner, resting a second before he came out for the next round—in a long line of next rounds. The thing he was fighting, you couldn't whip it for good. All you could do was keep on whipping it till you couldn't come out anymore and somebody else had to take your place" (316). Jean Rhys' Antoinette wages a similar battle for justice. Shortly before her transformation into Bertha Rochester, Antoinette confronts her husband, and all the patriarchal and colonizing social attitudes that he represents, in the name of justice: "'Justice,' she said, 'I've heard that word. It's a cold word. I tried it out,' she said, still speaking in a low voice. 'I wrote it down. I wrote it down several times and always it

looked like a damn cold lie to me. There is no justice.’” (Rhys 94). Even when justice is served, the right to live freely outside dominant cultural constructions of what it means to be ‘normal’ in terms of race, gender, sexuality and ability is a battle to be fought, on different fronts, over and over again. At a time when policy is increasingly identifying societal integration as the solution for disability, popular Reform era novels do not share that confidence in society’s capacity to be a safe place for people who deviate from the social norm.

### **Institution as Asylum**

In 1971, after a comprehensive review, Walter B. Williston described the institutional facilities for mentally retarded people in Ontario in the following terms:

The wards of these institutions are almost universally large, combining persons of different ages, degrees of retardation and varied handicaps. Living conditions tend to be dull, monotonous and impersonal. The wards are severely overcrowded; those which were designed to house 30 often accommodate over 50. The residents have few private possessions, and seldom is there space to store them. Any degree of personal attention or privacy is simply not possible. Generally, one immense building accommodates the residence, the hospital, and facilities for training, education and recreation. There is almost complete segregation of the sexes beginning in early childhood; co-educational activities are minimal. I have found that many of the wards are unnecessarily locked. In most cases males and females, even those who are only moderately retarded, must use lavatories without doors and often without toilet seats. (65)

Williston's report had significant implications for subsequent mental disability policy planning. By 1973, there was growing recognition in policy planning that "the problems faced by the majority of the mentally retarded are primarily of a social rather than a medical nature" (Welch 1). However, this recognition did little to disrupt the segregation of mental disability and mental illness policy streams. In his detailed descriptions of all the institutional facilities for mentally disabled people in Ontario, Williston notes that just at the Ontario Hospital, in Cobourg, "[t]here are some sixty to seventy residents who, in addition to being retarded, are suffering from some form of psychoses [sic]" (39). Even though both populations continued to require similar supports and even cohabited within the same institutions, pains taken to differentiate between lunacy and idiocy in the Establishment phase of the Cycle persist in the Reform phase.

In the Reform novels under analysis the institutions include those places designated for the control or cure of mental disability. In addition, other locations where characters with mental disabilities seek asylum from a society that discriminates against them are also considered. In the three novels under review here different institutions serve as an asylum: the hospital school where Danielle Valensky resides, in Krantz's *Princess Daisy*; the mental hospital where McMurphy serves his sentence, in Kesey's *One Flew Over the Cuckoo's Nest*; and the convent school in Rhys' *Wide Sargasso Sea*.

The emphasis on diagnosis and segregation of people who often need similar kinds of supports is depicted in Kesey's, *One Flew Over the Cuckoo's Nest*. The distinction here is made between the 'Acutes' and the 'Chronics' (15) who are regarded

as two populations who “don’t generally mingle” (Kesey 18), even though they occupy territory within the same ward.<sup>36</sup> Bromden describes how

[a]cross the room from the Acutes are the culls of the Combine’s product, the Chronics. Not in the hospital, these, to get fixed, but just to keep them from walking around the street giving the product a bad name. Chronics are in for good, the staff concedes. Chronics are divided into Walkers like me, can still get around if you keep them fed, and Wheelers and Vegetables. What the Chronics are—or most of us—are machines with flaws inside that can’t be repaired, flaws born in, or flaws beat in over so many years of the guy running head-on into solid things that by the time the hospital found him he was bleeding rust in some vacant lot.

But there are some of us Chronics that the staff made a couple of mistakes on years back, some of us who were Acutes when we came in, and got changed over.

(Kesey 15-16)

The Combine is Bromden’s concept of a machine that rehabilitates and assimilates society’s misfits. According to Bromden, the Chronics are casualties of assimilation procedures gone wrong, or they are people who have been born “simple” (Kesey 52). They are immune to the Combine. However, McMurphy does not acknowledge the distinction between the two groups when he comes onto the ward. Instead, after introducing himself to all the Acutes, “he comes right on over to the Chronics, like we aren’t no different... He shakes the hands of Wheelers and Walkers and Vegetables, shakes hands that he has to pick up out of laps like picking up dead birds” (Kesey, 22-23).

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<sup>36</sup> Williston’s report on the “Care and Supervision of Mentally Retarded Persons in Ontario” demonstrates that, in 1971, that substantial “mental retardation units” existed in psychiatric hospitals in Kingston, Lakehead and Woodstock (41-42). In all categories of special care facilities, mentally ill and disabled populations (‘acutes’ and ‘chronics’) co-mingled.

It does not occur to McMurphy not to speak to someone just because they may not answer. He insists on seeing all the patients on the ward in terms of what they have in common as human beings. Furthermore, the fact that Bromden is assigned the 'chronic' label even though he has an internal narrative suggests that the other "Wheelers and Walkers and Vegetables" may have one too.

In *Wide Sargasso Sea*, the convent school is a kind of reprieve from a cruel world for Antoinette, even while she learns its rules. At the convent Antoinette learns how to behave like a lady from the example of her classmates and the stories of the lives of the saints "who were all very beautiful and wealthy. All were loved by rich and handsome young men" (Rhys 29). These narratives help to prepare Antoinette for the role she will be expected to play in the outside world, or at least an idealized representation of what she should aspire to be. Without dwelling much upon the terrible suffering that these martyrs had to suffer in order to become beatified, the young Antoinette loves the escapism that these narratives offer. The convent boarding school is her

refuge, a place of sunshine and of death where very early in the morning the clap of a wooden signal woke the nine of us who slept in the long dormitory. We woke to see Sister Marie Augustine sitting, serene and neat, bolt upright in a wooden chair. The long brown room was full of gold sunlight and shadows of trees moving quietly. I learnt to say very quickly as the others did, 'offer up all the prayers, works and sufferings of this day.' But what about happiness, I thought at first, is there no happiness? There must be. Oh happiness of course, happiness, well. (31)

Antoinette appreciates the security that her asylum affords, even at the cost of a more active life in the wider world. She leaves her sanctuary at the age of seventeen. When her stepfather comes to collect her, he tells her "[y]ou can't be hidden away all your life"



(33). As her departure approaches, Antoinette cannot help but resent those who are able to stay behind: “They are safe. How can they know what it can be like *outside*?” (Rhys 34). For Antoinette, and most women of her time, the only way for her to live securely on the “Outside” is to be under the protection of a man.

While Antoinette’s asylum is a place for her to heal and learn, McMurphy’s decision to get himself transferred to the mental hospital is an attempt at exercising some control over the terms of his confinement. The hero of Kesey’s novel deliberately arranges his transfer to the mental ward as an asylum from the rigors of the penitentiary where he has served four months of a six month sentence on a work farm.<sup>37</sup> McMurphy’s patient file indicates that he has been sent to the mental hospital on the authority of a judge’s ruling that seems to have been imposed as a measure of discipline, rather than cure for an alleged psychosis. His file alludes to the possibility that he may be “feigning psychosis to escape the drudgery of the work farm” (Kesey 47). McMurphy is a burden passed from one custodial facility to another. He makes it clear that “I’m in this place because that’s the way I planned it, pure and simple, because it’s a better place than a work farm. As near as I can tell I’m no loony, or never knew it if I was” (Kesey 74). McMurphy’s ability to manipulate the system again points to the arbitrariness of diagnosis that can be influenced and even made up to serve the interests of the institutional placement system. For their part, the administration of the penitentiary was able to surrender responsibility for a uncooperative inmate.

While McMurphy sees himself as just passing through the ward, Krantz depicts a different type of institutional experience in her novel. *Princess Daisy* tells a story of

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<sup>37</sup> The residents at the Orillia and Rideau facilities also worked on farms—originally as labourers for the institutions, and later as low-paid labour for other area farmers, justified as work skills training (Reaume 133-180; Simmons, 1982, 102-106; Williston 23-29)

identical twins born into power and privilege who go on to lead very different lives because one sister is bright as well as beautiful, and the other is mentally disabled. The plot of the novel essentially revolves around the journey that one sister is compelled to undertake to protect the other and find a way to be able afford to keep her in an expensive institutional school. The ethics of institutional care for people with mental disabilities is not explored in this novel. Krantz simply incorporates the general medical wisdom considered at the time of the twin sisters' birth, in the mid-1950s, as expressed through the advice of the attending physician. He explains to their father the stresses and risks associated with raising a disabled child:

“There will be, in any case, the question of constant care, even with moderate retardation. With severe retardation the problem becomes enormous. Great watchfulness is necessary in all cases, throughout the child's life. Once the child can walk, there will always be danger. As puberty approaches, the problem becomes aggravated. Often an institution is the only answer.” (77)

In order for the reader to be sympathetic with Daisy's quest to maintain her sister in her asylum, Danielle's vulnerability outside of the institution and her attachment to the facility need to be accepted without question.

In *Princess Daisy* the School is more than an educational facility, a retreat, and a solution. It is Danielle's home, and the staff and residents become her surrogate family. Over time, even Daisy begins to lose the imaginative capacity to conceive of an alternative storyline for her sister, outside the institution:

she would imagine Danielle, her double, her other self, more her child than her sister, playing in the garden or singing the simple songs she had been taught, and hot tears would fill her eyes at the realization of all her twin was missing, all the

new knowledge and experience she would never have. Her only comfort was the realization that Dani was as happy as she could possibly be, that Queen Anne's School was truly home for her and that the staff and other patients had become her family. (Krantz 179-180)

From the time Danielle enters the institution there is no question of her leaving it. Even when Daisy moves to America, there is no suggestion that it might be appropriate for Danielle to relocate closer to her only family. Instead, the greatest kindness that can be done for Danielle is to maintain the structure of her life that she has learned in the institution.

Some have suggested that the bonds formed between residents and staff, the importance of structure and routine, and the difficulties with transition that many people with severe mental disabilities experience have not been adequately taken into account in the de-institutionalization process ("Lifetime Friendships Lost", 12 July 2008). While there is some expert opinion from this time to support the contention that re-integration into the community is not the ideal option for all people who have spent most of their lives in the institution, the drive to close down the institutions in Ontario ultimately prevailed. In his report to the Minister of Health, Walter Williston suggests that it "is too much to expect that any person could spend years in a large institution and, after having been 'discharged' into a strange community, be able to cope with the problems that will beset him in the outside world" (5). Therefore, his policy recommendations were for long-term planning to incorporate a range of services in all communities so that the institution does not need to be considered as the only viable option for people who have severe mental disabilities.

Reform policy discourse was more optimistic than the storylines of many Reform-era novels about the capacity of people with mental disabilities to succeed in communities that are portrayed as fearful, intolerant, or unable to accommodate diverse abilities and needs. In Welch's "New Policy Focus", he contends that mentally retarded people "may require an environment that is protective and highly structured. It must be stressed, however, that *special treatment does not necessarily imply or demand segregation of the retarded*" (4 emphasis in original). Williston and Welch both wanted to see community capacity enhanced to the extent that institutionalization was recognized as a last resort for people with mental disabilities. However, Williston would agree with the narrator of Danielle Valensky's story: After spending her life, from the age of six, in the same facility, she will not grow and change to be able to thrive in the wider community. Likewise, the community will not grow and change to adequately accommodate the way she is (Williston 67).

This is a position shared by Dr. Bruce D. McCreary, to whose testimony Judge John Matheson refers in his decision on *Clark v. Clark*. McCreary testified that it was his "professional opinion that Justin's mental development, physical problems and life experiences, which have been essentially confined to an institutional environment, are such that he should be regarded as incompetent" (para. 32). However, Judge Matheson found the evidence given by the professionals who worked with Mr. Clark on a regular basis to be more convincing. As a result, Judge Matheson found Mr. Clark competent to make the decision to leave the institution to move to a supported-living home in the community.<sup>38</sup> The lack of consensus around the best care alternatives for people who

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<sup>38</sup> In March 2008, Helen Henderson reported that Justin Clark moved from the Rideau Regional Centre in 1983 "into a house in Ottawa with two long-time friends. He also travelled the world—from Switzerland to

have lived most of their lives in an institution speaks to the diversity of this population. To be effective, any policy needs to be flexible to accommodate the specific capacities and desires of each person affected.

Justin Clark's family does not appear to have maintained a personal relationship with their son from the time he was admitted to the institution, at the age of two. When he learned to communicate using Blissymbols many of his questions were about his family (Clark v. Clark, para. 13). This circumstance was not unusual, as for many years contact between families and their retarded children who resided in an institution was not actively encouraged. In many cases, the relationship that Daisy maintains with her sister, over years, and across great distances just would not have been possible. Institutions for people with mental disabilities in Ontario were almost always located in rural areas. For example, in 1971 the catchment admission area for the Rideau Regional Hospital School was 176,600 square miles (Williston 21). Large distances between family homes and isolated institutions, together with restrictive institutional policy conspired to effectively undermine family ties.

Williston further explains that "admission procedures were rather heartless, with no opportunity for pre-admission visits, and an almost knife-like separation at the moment of admission; any communication with the family came only from the individual initiative and dedication of a member of the staff" (30). Such a scene is played out in *Princess Daisy*:

The dedicated professionals who ran the institution were accustomed to, as they put it, "unfortunate scenes" when a child was finally left in their excellent care, but

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Nicaragua, where by all accounts his Bliss board became a useful bridge between two languages. These days, Clark prefers to stay out of the spotlight, declining interview requests. Friends say he lives quietly in that same Ottawa house and works as a computer consultant" (L11)

nothing had prepared them for the parting of Daisy and Danielle. All of them who were unlucky enough to be present found themselves in despair and some of them were reduced to unprofessional tears by the time Stash finally pried Daisy away...

(Krantz 123)

On her wall, Danielle keeps pictures that her sister draws and sends her, along with photographs taken of the two of them together during regular visits that Daisy tries to sustain over the years, except when the cost of keeping her sister in the institution makes traveling to visit her prohibitive. In this small detail the reader is given a point of comparison to the Ontario institution where the residents lived in wards, with no room to store or display personal possessions (Williston 65).

In large scale institutional facilities, internal policies tended to emphasize structural authority and predictable routine, even down to personal hygiene regimens.<sup>39</sup> In Kesey's novel, McMurphy forces his fellow patients to confront this reality by habitually making a mockery of official policy that serves no legitimate purpose other than enforcing the dependence of the patients. On his first morning in the ward, he is unable to brush his teeth because it is ward policy to keep the toothpaste locked in the cabinet until six-forty-five:

“Locked in the cabinet, is it? Well well well, now why do you reckon they keep the toothpaste locked up? I mean, it ain't like it's dangerous, is it? You can't

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<sup>39</sup> In the *Globe and Mail* (27 July 2010), Beth Marlin reports on a prospective class-action suit being launched against the Huronia institution in Orillia, covering thousands of former patients: “Marilyn Dolmage, whose brother, born with Down syndrome, died of untreated pneumonia at Huronia when he was eight years old, worked as a social worker there from 1968 until 1973 and has kept in touch with several of its residents. ‘They had all of their citizenship rights stripped away. They had no control over their lives. They were lined up to eat, they were lined up to shower,’ says Ms. Dolmage. adding that she also witnessed residents being tranquillized, kept in caged cots and sprayed with a water hose after eating” (para 9-10).

poison a man with it, can you? You couldn't brain some guy with the tube, could you? What reason you suppose they have for puttin' something as harmless as a little tube of toothpaste under lock and key?"

"It's ward policy, Mr. McMurphy, tha's the reason." And when [the orderly] sees that this last reason don't affect McMurphy like it should, he frowns at that hand on his shoulder and adds, "What you s'pose it'd be like if *evahbody* was to brush their teeth whenever they took a notion to brush?" ...

"Yes, now, I do [see]. You're saying people'd be brushin' their teeth whenever the spirit moved them." (Kesey 93)

The episode speaks to a recurring question in policy planning generally: Whose needs does the policy serve? Is the intention to promote independence, choice and self-actualization, or merely to reinforce relations of power and dependence?

The pressure to accommodate a large, diverse population at minimal expense is evident in Williston's evaluation of Ontario's residential infrastructure for mentally retarded people. He found that most facilities, especially the largest ones, had a staffing complement that was about 20-40% lower than the standard set for this service sector by the American Association for Mental Deficiency (36-40). Following Williston's and Welch's reports, the Developmental Services Act was passed in 1974 to address the transfer of responsibility of developmental disability policy from the Ministry of Health to the Ministry of Community and Social Services. In addition, it facilitated the transfer of residential care from the Provincial institutions to community living agencies and residential facilities.

Moving away from the institutional model was clearly promoted as a significant cost saving initiative, as Welch indicated the "the share of capital costs underwritten by

the Government of Ontario for any program in an institution for the mentally retarded is 100 per cent; [and] the share of capital costs taken for programs in the community is a maximum of 50 per cent” (7). With such chronic shortages of support staff on large wards of people with very complex needs it is difficult to maintain personal safety, much less realize a stimulating environment with any individual attention or personal engagement. In his novel, Kesey alludes to emphasis on fiscal restraint as a priority in the administration of the asylum. The description of the ward makes note of a commendation on the wall that says “CONGRATULATIONS FOR GETTING ALONG WITH THE SMALLEST NUMBER OF PERSONNEL OF ANY WARD IN THE HOSPITAL” (18). Creating ‘efficiencies’ in terms of personnel generally leads to less personalized therapeutic care and more reliance on drug therapy to control behaviours (Armstrong & Armstrong 86-87). In addition, isolation of frontline staff often leads to neglect or episodes of abuse (White, Holland, Marsland & Oakes 7).

Given the legacy of under-funding and controversial treatment that became associated with institutional care, it is not surprising that Williston concluded that “a century of failure and inhumanity in the large multi-purpose residential hospitals for the retarded should, in itself, be enough to warn of the inherent weakness in the system and inspire us to look for some better solution” (68). However, even where the institution is reviled, in the Reform novel it still often is depicted as a refuge from an even more cruel world. In Kesey’s nightmare vision of the mental hospital the institution is still perceived as a preferable option to trying to navigate the barriers and discriminating attitudes so prevalent on the Outside. When McMurphy realizes that most of the people on the ward are voluntary patients he is incredulous: ““Tell me why. You gripe, you bitch for *weeks* on end about how you can’t stand this place, can’t stand the nurse or anything about her,



and all the time you ain't committed. I can understand it with some of those old guys on the ward. They're *nuts*. But you, you're not exactly the everyday man on the street, but you're not *nuts*"" (Kesey 195, emphasis in original). When McMurphy asks Billy Bibbit, specifically, why such a young man would choose to be in the ward instead of driving a car and meeting girls, he reduces him to tears:

“You think I wuh-wuh-wuh-*want* to stay in here? You think I wouldn't like a con-con-vertible and a guh-guh-girl friend? But did you ever have people l-laughing at you? No, because you're so b-big and so *tough*! Well, I'm not big and tough. Neither is Harding. Neither is F-Fredrickson. Neither is Suh-Sefelt. Oh—oh,you—you t-talk like we stayed in here because we liked it! Oh—it's n-no use...” (Kesey 195)

As hard as life on the ward may be, the structure that it provides is security. Furthermore, under Ratched's direction, the therapy only reinforces dependence and destroys self-esteem. Making community re-integration even more difficult is the stigma associated with having spent time in an asylum for the mentally ill or retarded (Williston 67).

The asylum that the institution offers is further affirmed at the end of the novel when the patients plot McMurphy's escape. It is noted that “the police never press too hard to pick up AWOLs from the hospital because ninety percent of them always show back up in a few days, broke and drunk and looking for that free bed and board” (Kesey 306). Reaume's research into patient files at Toronto's Hospital for the Insane confirms that, historically, escaped patients sometimes did return of their own accord (198).

Even Bertha Rochester's confinement is construed as an act of mercy by the woman employed as her personal attendant. At the conclusion of *Wide Sargasso Sea*, Grace Poole reflects upon the terms and conditions of her employment as the custodial

caregiver for Rochester's mad wife, as well as her reasons for accepting them. She muses that

*'...[a]fter all the house is big and safe, a shelter from the world outside which, say what you like, can be a black and cruel world to a woman. Maybe that's why I stayed on.'*

*The thick walls, she thought. Past the lodge gate and a long avenue of trees and inside the house the blazing fires and the crimson and white rooms. But above all the thick walls, keeping away all the things that you have fought till you can fight no more. Yes, maybe that's why we all stay—Mrs Eff and Leah and me.*

(Rhys 115)

Grace Poole is well paid to make sure that Antoinette/Bertha Rochester's subsistence needs are met and that her existence remains hidden. In this version of her story, Rochester's wife has quarters that are spacious and she gets outside occasionally; but she is not like McMurphy who chooses the institution, nor like Danielle who is happy there because she has no memories of any other home. Bertha has no choice; she waits in vain for Rochester to come so that she can plead her case for emancipation (Rhys 115). She has her memories of a time before her confinement, and these contribute to her madness and drive her desperate escape.

Like Bertha, McMurphy is only able to escape his captivity in death. His refusal to accept the terms of his incarceration eventually breaks down his mind and precipitates his own demise. Looking back, Bromden muses on its inevitability: "It was like he'd signed on for the whole game and there wasn't any way of him breaking his contract" (Kesey 310). Starting with the return from the fishing trip, there are increasing allusions to McMurphy looking tired and worn out, and on the morning of his last battle with

Ratched he “looked sick and terrifically tired” (Kesey 311). When McMurphy advances on Ratched to commit his final, and ultimately fatal, act of resistance, Bromden is aware that

[w]e couldn’t stop him because we were the ones making him do it. It wasn’t the nurse that was forcing him; it was our need that was making him push himself slowly up... It was us that had been making him go on for weeks, keeping him standing long after his feet and legs had given out, weeks of making him wink and grin and laugh and go on with his act long after his humor had been parched between two electrodes. (Kesey 318)

In the institution McMurphy is transformed from egoist to advocate. He has helped others to see how their asylum was actually making them more sick and too dependent upon authority to ever really survive on their own. McMurphy’s success at undermining institutional authority costs him his mind and his life.

McMurphy is able to exercise greater influence over the terms of his segregation than either Bertha Rochester or Danielle Valensky. Still, his choice to get himself removed from one institution (the penitentiary) to what he perceived as an asylum is ultimately his death sentence. In Rhys’ version of the life-story of the ‘madwoman in the attic’ there is no justice in Bertha Rochester’s demise. As her husband’s captive, she is left with no one to hear her story and eventually she loses her voice altogether. However, McMurphy has become the martyr that Ratched always feared he would become. Her patients have become “immune to her poison. Their eyes met hers; their grins mocked the old confident smile she had lost” (Kesey 313), and the “enamel-and-plastic face was caving in” (Kesey 314). McMurphy dies, but not before empowering the others to choose to leave their asylum and return to find their place on the Outside (Kesey 319). In

contrast, Danielle Valensky is a passive player in her own story whose existence affects other people's relationships, while she is locked in time in the mind of a three-year-old. Safe in her high-priced institutional school, Danielle survives because she is insulated from the world and its torments.

## **CHAPTER 8- Analysis of Dismantlement Phase (1987-2009)**

### **Introduction**

A policy commitment to phase out institutional residency for people with mental disabilities was first articulated in Ontario's Challenges and Opportunities Initiative. Developed in 1987, it was heavily influenced by the 1971 Williston report (Government of Ontario, 1987, 4). At the outset of the Dismantlement phase, the downsizing of the institutional system was already underway in Ontario, although Simmons cautions that it is difficult to ascertain reliable discharge rates as, initially, many people were simply transferred from one type of institutional facility to another (1982, 313). However, by 1987 there were "14 directly operated... and 10 board-operated... facilities, serving an estimated 5,200 persons" (Government of Ontario, 1987, 22). By 2009 the three remaining provincial institutions dedicated to the care of people with mental disabilities were all closed, despite vocal resistance and a failed court challenge by some family members who had placed their relatives into institutional facilities as children, "with the promise that they would be looked after forever"(Parsons 16). However, celebration over the official end of the institutional era has generally overwhelmed voices of concern for the well-being of severely disabled people living in less structured environments with, arguably, less direct oversight and enforcement of legislated standards.

The Ministry of Community and Social Services is responsible for enforcing the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, which received Royal Assent on October 8, 2008. This legislation was designed to replace the Developmental Services Act that had regulated care for people

with mental disabilities within provincial facilities since 1974. Although some key sections of the new legislation have yet to be formally enacted, it emphasizes the objective of individualized service planning to support a population with diverse daily living needs in the community.

The Ministry of Health and Long-Term Care has also pursued a community integration mandate for people who once would have resided in mental hospitals for long periods of time with a diagnosis of mental illness. The 2006 Kirby Report highlights the insecure living conditions of thousands of Canadians who are disabled as a result of chronic mental illness; it demonstrates that many of the issues raised by and on behalf of people diagnosed with mental illness are almost identical to those identified in mental disability policy discourse, including: the need for enhanced and individualized community services, accessible supported housing, supports for family members, and policy that works to eradicate the enduring stigma attached to having a mental disability.

As society comes to terms with a shift in emphasis in responsibility from government to community, from expert-driven models of care to the expertise of individuals and family in designing life plans, role confusion and gaps in service are bound to occur. In an era of change and uncertainty, it is not surprising that Dismantlement novels look to the past in writing contemporary narratives about people with mental disabilities in the community. Timothy Findley's *The Piano Man's Daughter* (1995) begins at the end of the nineteenth century and spans the life of three generations of the Kilworth family, until 1945. Kim Edwards' *The Memory Keeper's Daughter* (2005) is set primarily in the Reform phase of the Cycle. A more contemporary perspective is offered in Marc Haddon's *The Curious Incident of the Dog in the Night-*

*time* (2003), which is set in a suburb of London and incorporates some of the modern-day environmental challenges faced by an adolescent boy with autism.

Given a growing sensitivity to diversity that individualized planning implies, it also makes sense that each of the novels selected for analysis depicts characters with different manifestations of disability. In Findley's novel, Lily Kilworth is, in her words, "not disabled... merely hampered" (273) by a mental illness that is never specifically diagnosed; Haddon's hero, Christopher Boone, is autistic; and in Edwards' novel Phoebe Gill has Down syndrome. While the authors have created characters whose stories are influenced by their respective disabilities, their outcomes are determined by their relationships with others, as well as by their place in their communities.

### **How Their Stories are Told**

The final phase of the Cycle reveals a noticeable increase in the range of perspectives that appear to contribute to policy planning and evaluation. In terms of policy development, there is evidence of a concerted effort to consult directly with those people most affected by changes in disability policy objectives in a post-institutional era. A number of planning documents and evaluations quote extensively from service users and family members (Kirby 2006; Marin 2005; Government of Ontario 2006; Parsons 2006). The Ministry of Community and Social Services also produced a "Guide on Person-Directed Planning" (Dingwall, Kemp & Fowke, 2006) that concludes with two personal narratives produced with the assistance of family members to demonstrate the empowering potential of person-directed planning.

In addition, there has been a number of memoirs and biographies published in recent years about the life-stories of people with a range of mental disabilities, their

relationships with family, and their communities.<sup>40</sup> Access to more individual stories may enrich planners' understanding of how policy affects personal lives, but it is difficult to determine the extent that consultation influences policy planning in a meaningful way. For example, Ellen Gambrill identifies social work as an "authority-based profession" in which "penetrating critiques of accepted views... are ignored or dismissed rather than carefully read, accurately presented, and carefully critiqued" (168). Claudia Malacrida argues that individuals with intellectual disabilities are so "devalued and stigmatized" (406) that their testimonies are undermined. Close family members are generally portrayed in contemporary policy consultations as reliable advocates. However, the novels considered in the Dismantlement phase suggest that perspectives offered by personal caregivers are influenced by their own needs or protective impulses that may oppose personal life choices that their child, sibling, or spouse might wish to make for him or herself.

Different narrators of the same person's life story will not necessarily emphasize the same life events. In Findley's *The Piano Man's Daughter*, Charlie Kilworth spends his life trying to learn from his mother's story who his father is; but for Lily this is simply not an important part of her narrative. Charlie learns the story of his mother's life largely through her own telling, but she has a confusing and unorganized way of giving her life story "—all of it sliding sideways, drifting off in little dots—all her sentences unfinished, the way her life was lived—everything always a beginning before there could be an ending to the part that went before" (Findley 6). In his own version of his mother's life,

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<sup>40</sup> A partial list includes: Brown (2009) *The Boy in the Moon*; Greenberg (2008) *Hurry Down Sunshine*; Inman (2010) *After her Brain Broke: Helping my Daughter Recover her Sanity*; Menzies (2009) *Enter Mourning: A Memoir on Death, Dementia, & Coming Home*; Thomson (2010) *The Four Walls of My Freedom*. These nonfiction narratives add to the range of perspectives that inform disability studies.



Charlie begins by recounting the circumstances of Lily's death: "She had died by fire as she had lived, in a circle of strangers. For once, she had made no attempt to escape. Her running—at long last—came to its end in the Asylum for the Insane at Whitby, Ontario, on Monday, the seventeenth of July, 1939. One month after her forty-ninth birthday" (Findley 6). Charlie's life-long sense of responsibility for his mother, along with his grief, influence how he tells her story. Still, the integrity of Charlie's version of Lily's life narrative is reinforced in a number of different ways. For example, Charlie explains that his rendition of Lily's account of her early years is corroborated and further informed by the testimony given by his grandmother, Ede Wyatt. Furthermore, much of Charlie's storyline is also drawn from Lily's own record of her life, which she has kept safely stored in the wicker basket that has never failed to accompany her when she makes an "escape" (Findley 10-11).

At the same time, Findley reminds the reader that a first-person narrative is not necessarily the truest life-story. Charlie faithfully recalls Lily's lies as well as her truths such as when she tells her brother, Liam, about a confrontation with her stepfather, Frederick Wyatt, which never happened (Findley 367). On another occasion Charlie recalls his mother recounting how "*Frederick used to lock me up there [in the attic] in the dark...* But Frederick had never locked her in the dark. The dark was a state of mind she could not escape—and she blamed him for it, though in her lucid moments I think she knew better. He was not the monster she made of him" (Findley 438). Findley succeeds at making Charlie's version of Lily's story credible because he is a character who can hear the authentic voice—in pianos and in people:

Every piano has its own voice—unique in its sound as the voice of a human being.

And when that voice begins to waver—when it strays, the way human voices do

under stress—my job is to restore its resonance—tighten its enunciation—clarify its tone. I have an unerring ear for these voices. That is my gift. In the music business, we call it *perfect pitch*. (Findley 8-9)

By paying attention to all the different sources and versions of Lily's story, against his own memories their life together, the reader accepts that Charlie is telling his own true story.

Dismantlement novelists are trying to represent the stories of characters with mental disabilities in a number of different ways. In Haddon's *The Curious Incident of the Dog in the Night-time*, Christopher Boone tells his own life story as he tries to solve the mystery of who killed the neighbour's dog, which he discovers impaled with a garden fork on Mrs Shears' lawn. However, because Christopher is autistic his ability to give a comprehensive life narrative or solve a murder mystery is challenged in interesting ways. His disability profoundly impairs his capacity to comprehend anything that is not communicated directly, in a matter-of-fact manner. Metaphor, symbolism and information that may be inferred through body language elude him. This is why Christopher finds people "confusing... for two main reasons. The first main reason is that people do a lot of talking without using words. Siobahn says that if you raise one eyebrow it can mean lots of different things. It can mean 'I want to do sex with you' and it can also mean 'I think what you just said was very stupid'" (Haddon 14-15). The other reason that Christopher finds people confusing is that they "often talk using metaphors" (Haddon 15). He explains what metaphors are and concludes that metaphors are lies. On the other hand, when he observes that the police inspector's hairy nostrils looked "as if there were two very small mice hiding" (Haddon 17) in them, he explains this as a simile, "which means that it really did look like there were two very small mice hiding in his

nostrils, and if you make a picture in your head of a man with two very small mice hiding in his nostrils, you will know what the police inspector looked like. And a simile is not a lie, unless it is a bad simile” (Haddon 17). Christopher’s ability to grasp humour is also impaired. Therefore, he advises the reader that “[t]his will not be a funny book. I cannot tell jokes because I do not understand them” (Haddon 8). However, the ensuing narrative is often very funny precisely because of Christopher’s inability to recognize things that most people would consider humorous.<sup>41</sup>

In *The Memory Keeper’s Daughter*, Kim Edwards takes a more conventional approach in her portrayal of Phoebe Gill by not giving her a substantial narrative voice.<sup>42</sup> Edwards uses the same plot device employed by Krantz, in *Princess Daisy*, in contrasting the life experiences of twins: one who is born normal, and the other with a mental disability.<sup>43</sup> As in Krantz’s novel, the babies’ father suffers from a childhood trauma that prevents him from accepting the disabled daughter; and David Henry succeeds in convincing his wife, Norah, that Phoebe has died at birth. However, unlike in Krantz’s novel, Phoebe’s presence is felt throughout the narrative, as the other major characters narrate their own stories, which have all been shaped by Phoebe’s existence in the world. Even though the story is never given from her perspective, Phoebe is present in every

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<sup>41</sup> Authors incorporate the voice of a mentally disabled narrator to critically comment upon disability and society in different ways. For example, Clare Allan’s (2006) *Poppy Shakespeare* depicts a first-person narrator who self-identifies as “dribbler”: “[f]act is I been dribbling since before I was even born. My mum was a dribbler and her mum as well, ’cept she never seen her hardly, grown up in a home while they scooped out bits of her mother’s brain, like a tater, taken the bad bits out, till she never knew she had a daughter no more and all she could do was dribble and shit” (3). Personality intersects with the narrator’s disability in a way that allows her to give an uninhibited perspective on the mental health system and the characters belonging to it; and she lavishly engages in hyperbole and other narrative devices of effective satire.

<sup>42</sup> In this respect, Edwards’ novel resembles Karen Bender’s (2000) *Like Normal People*. Lena is a woman who is mentally disabled, and her life story is told from the perspectives of her mother, sister and niece. Although the action of the story and, in fact, the life experiences of all the other characters are determined by their relationship to Lena, her story is never given directly, from her point of view.

<sup>43</sup> Wally Lamb’s novel (1998), *I Know This Much is True* also tells the story of twins, one of whom has a mental disability.

chapter of the novel, or at least her memory is evoked as the thread that ties all the other characters' storylines together. Furthermore, Phoebe is depicted as a character who grows and changes along with the other characters in the novel. Even though she does not give much of her own story, those who do speak for Phoebe tell her story with enough insight and detail to make her a fully formed character, in her own right.

Although the mentally disabled characters considered in this phase of the Cycle can all speak for themselves, at crucial points in their respective stories Lily Kilworth, Christopher Boone and Phoebe Gill need advocates to speak for them. At the same time, however, their presence also contributes insight into the limitations of the other major characters in Findley's *The Piano Man's Daughter*, Haddon's *The Curious Incident of the Dog in the Night-time*, and Edwards' *The Memory Keeper's Daughter*.

### **The Role of the Family**

Premier David Peterson's letter that prefaces the Province of Ontario's Challenges and Opportunities Initiative opens by expressing "great pleasure in offering my encouragement and support to the parents of developmentally-handicapped residents in Ontario". The identification of his primary audience is telling. From the outset of the Dismantlement phase it is clear that the realization of policy objectives related to mental disability services and supports rely most heavily upon the active participation of families. The substance of much of the policy debate revolves around how much, and in what ways, the caregiving work of families should be supported by the community, and how much by government programs. This sub-chapter considers how cultural assumptions about parents, siblings, and children as caregivers intersect with Dismantlement policy objectives. The novels considered in this phase of the Institutional

Cycle challenge the assumption made in policy planning that family members are always the best qualified to offer the most authentic version of the disabled individual's life story.

Findley portrays the conflict that parents often experience in trying to reconcile their own dreams with their children's needs. When a child has a mental disability that demands extraordinary vigilance, it is not unusual for parents to experience feelings of exhaustion, frustration and even resentment. By the time Lily Kilworth is seven years old, her mother, Ede, is already struggling with how to provide for her education, her entertainment, and her care, even though she has a secure home and a supportive extended family at hand who also love the child (Findley 80).

To some extent Ede Kilworth's concern for Lily is that of any anxious parent carefully watching over the growth of their child, but by the time Frederick Wyatt enters their lives Ede already realizes that Lily will require accommodation and protection for the rest of her life (Findley 134).<sup>44</sup> Therefore, when Frederick proposes to her, Ede debates with herself whether Lily is an insurmountable obstacle to marriage with this man:

Lily. *The cause of all my joy. And all my grief.*

Don't say that. It isn't true.

Ede dropped the curtain, shutting out her vision of Frederick.

It wasn't true. It wasn't.

And it was.

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<sup>44</sup> Thinking about his own experience raising a child with severe disabilities, Ian Brown asks whether the parenting journey that he and his wife have known is very different from what other parents experience: "But let me ask you this: is what we've been through so different from what any parent goes through? Even if your child is as normal as a bright day, was our life so far from your own experience? More intensive, perhaps; more extreme more often, yes. But was it really different in kind?" (75)

She turned back into the room and began to undress.

*If only Lily...*

No. She must not think that. She must never think that again. She had thought it once in the throes of some despairing moment. She had thought it and said it—cursing the child to her face. For some denial of access to a moment's freedom—for being the impediment between the life Ede wanted and the life she had: *damn you!* Meaning: *damn you for being born!*

*But oh—if I should ever say that again. Or think it.* (Findley 102)

Resentment and guilt commingle in Ede's desire to lead a normal life.<sup>45</sup> Ultimately, Ede does decide to accept Frederick's proposal, but waits until after their marriage to disclose Lily's disability. Her new husband makes it clear that her daughter's disability is hers to manage and that he will not tolerate Lily's behaviour becoming an obstacle to his ambitions. From this point forward, Ede's role as Lily's advocate is tempered by her primary duty to promote her husband's professional and social interests.

Throughout the Institutional Cycle, the advocacy of parents has been identified as a catalyst for policy change. However, the novels considered in the Dismantlement phase also portray, in different ways, how the challenges of coping with the mentally disabled individual's impairments sometimes make it difficult to have confidence in their abilities. In learning how to be the impeccable, polished status symbol that Frederick wants her to be, Ede loses herself and her ability to love Lily for who she is. This is evident in

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<sup>45</sup> Brown discusses the kind of conflict parents with disabled children have with themselves, or in relation to societal expectations of how they should live their lives. He recalls a conversation with Fergus and Bernice McCann, whose daughter, Melissa, has a similar diagnosis (CFC) as his own son: "What drove Fergus especially crazy was that because of Melissa, he wasn't allowed to have the same impulses and desires the rest of the world had—because to have regular ambitions for our own life meant you were putting yourself first, or even momentarily ahead of your all-consuming child" (148).

Charlie's recollection of Ede's reaction to Lily's academic achievement that earns her a scholarship to Cambridge University:

That my mother was an *intellectual* had long been evident—but *brilliant*? Ede was at a loss. She kept the [acceptance] letter to herself and its description of Lily's talent was not transmitted. I heard of it only after my mother's first incarceration at the Lunatic Asylum on Queen Street in Toronto.

*She indulged in too many dreams*, Ede said. *Her brilliance was a curse*. She claimed to have known this all along—but I doubt it. I think Ede's fears for Lily blinded her to some of Lily's wonders. (Findley 306)

Lily's mental disability contributes to episodes of active psychosis that compel her need for escape, as well as catatonic lapses that render her oblivious to her surroundings, but her intelligence, particularly her creative capacity, is not impaired. However, the nature of Lily's symptoms call upon Ede to commit her energies to protecting Lily from potential consequences of those behaviours that make her daughter vulnerable. As a result, she fails to recognize the abilities that set Lily apart.

Edwards' *The Memory Keeper's Daughter* depicts how important advocacy is for many parents and the prospects of their children. When Caroline assumes responsibility for Phoebe, she also takes it upon herself to learn everything she can about Down syndrome in order to minimize its disabling influence on Phoebe's life. This puts her in contact with other parent advocates:

Caroline would never forget those hours, the excitement she'd felt, as if she were waking from a long, slow dream. What would happen, they conjectured, if they simply went on assuming their children would do *everything*. Perhaps not quickly. Perhaps not by the book. But what if they simply erased those growth and

development charts, with their precise constricting points and curves? What if they kept their expectations but erased the time line? What harm could it do? Why not try? (Edwards 98)

For Caroline, being Phoebe's advocate gives her life purpose, and her professional expertise as a nurse helps inform her research and her understanding of professional attitudes about disability.

However, Caroline's enthusiasm for insisting on Phoebe's rights and abilities are eventually supplanted by anxiety about the prospects of Phoebe growing up, leaving home, and possibly getting married. When she is approached by the director of the day centre that Phoebe attends to discuss Phoebe's emerging sexuality, Caroline refuses to address this reality. Her anxieties about Phoebe's capacity to live independently, as well as her inability to imagine her life without having Phoebe to care for, are all mixed up in Caroline's vision of Phoebe's future life when she tries to explain her concerns to her husband:

"I just can't imagine her out in the world. And she certainly can't get married, Al. What if she did get pregnant? I'm not ready to raise another child, and that's what it would mean."

"I don't want to raise another baby either," Al said.

"Maybe we should keep her from seeing Robert for a while."

"Al turned and looked at her, surprised. "You think that would be a good thing?"

"I don't know," Caroline said. "I just don't know."

"Look here," Al said gently. "From the minute I met you, Caroline, you've been demanding that the world not slam any doors on Phoebe. *Do not*



*underestimate her*—How many times have I heard you say that? So why won't you let her move out? Why not let her try? She might like the place. You might like the freedom. Why have you worked all your life, if not for some kind of independent life for Phoebe?" (Edwards 346-347)

While policy-makers have come to depend upon parents to support people with mental disabilities, the novels show that not all parents have the resources to be effective advocates. Contemporary analysis of access to support services for people with developmental disabilities has found that "parents who are well educated and articulate appear to have a much greater chance of obtaining funding for services for their family members than those parents without the skills required to effectively advocate for their child" (Parsons 8). People with mental disabilities especially need to count on the capacity of family members to speak for them when they have communication impairments, or simply because their own voices carry little authority.

Whereas Caroline has embraced the role of being Phoebe's mother, Haddon's novel depicts a mother who has trouble sustaining the effort required to provide for her son's needs. Christopher Boone's mother is a woman who feels exhausted and lonely in her role as the parent of a child with severe behavioural impairments. When she leaves the family, Christopher's father acts out of feelings of helplessness and resentment by telling his son that she has died from "a problem with her heart" (Haddon 23). However, Christopher finds the letters that his Mother has been writing him; and he learns how being his mother affected her decision to leave:

*I was not a very good mother, Christopher. Maybe if things had been different, maybe if you'd been different [sic.], I might have been better at it. But that's just the way things turned out.*

*I'm not like your father. Your father is a much more patient [sic.] person.*

*He just gets on with things and if things upset him he doesn't let it show. But that's not the way I am and there's nothing I can do to change that. ( Haddon 106)*

Christopher's Mother's feelings of inferiority as a parent partially explain her loneliness within the family and her decision to leave her son in the care of his father, who she perceives to be the better parent (Haddon 107). She tries to explain how observing Christopher with his Father validated her decision to leave with Mrs. Shears' husband because he was lonely in his marriage too:

*you didn't shout at one another. And it made me sad because it was like you didn't really need me at all. And somehow that was even worse than you and me arguing all the time because it was like I was invisible.*

*And I think that was when I realized you and your father were probably better off if I wasn't living in the house. Then he would only have one person to look after instead of two. (109)*

A dominant cultural value, as portrayed in its stories, is that good mothers do not leave their children. Many people would struggle to sympathize with this mother's frustration, loneliness, and her decision to escape the responsibility of parenthood. However, Christopher's mother is just a regular person who makes spelling mistakes, holds a small job, reads cheap novels, and wishes that her life was different. She does not have the same range of personal resources as the mothers in other novels in this sample: Caroline Gill has professional expertise as a nurse to organize and advocate for Phoebe's right to attend school and access existing community supports; and Ede Kilworth Wyatt has an extended family and a household staff to help her meet her child's needs.

The prominent role that Christopher's father takes in his son's care marks another notable shift in the representation of family roles that have typically privileged the maternal bond with a disabled child. When confronted by his wife's outrage at the revelation that he had told their son that she had died, Christopher's father defends himself as a loving parent. When she points out the injustice of wiping her "out of his life altogether", he questions whether this is not what she really wanted (196). Christopher's father's role as his son's primary caregiver is just one dimension of the greater diversity of roles and family models in Dismantlement-era novels in comparison with previous phases of the Cycle.

Christopher's father tells his son that his mother has died rather than attempt to give a complicated and painful explanation about why she has left them, and the other novels also explore how parents and other familial caregivers will deceive themselves and others in order to rationalize choices that they make on behalf or because of their disabled children. This, in turn, imposes limitations on the veracity of any life narrative offered by a familial spokesperson who is presumed to know the individual best. In Findley's novel, Charlie lives with the guilt of one particular episode when he denied his relationship with his mother altogether, in order to avoid the embarrassment of coming to Lily's aid when she needed it:

It happened in a public place—the quad at King's College, where I had been sent when still a boy. The occasion, I guess, was some sort of parents' day or prize day—I don't remember. The memory of what I did overwhelms it.

Lily had one of her episodes and fell to the ground. There were a lot of people there and I was mortified.

"She's fainted," someone cried. "We must get a doctor!"

But I knew she hadn't fainted. I knew too well precisely what was happening and what was going to happen next and I could not bear to be present when it happened in that particular place.

"Does anyone know who this woman is?" someone asked.

No.

I was silent. I turned away. And ran. And left her to the mercy of her demons, anonymous and alone. (Findley 11-12)

When family members sometimes struggle to endure the complications of loving someone with a severe mental disability, it may seem sensible to ask how policy makers can reasonably expect their acceptance and inclusion within the wider community.

Both Charlie and Ede live with the guilt of the limitations of their personal abilities that prevent them from always being able to protect Lily. When her daughter is finally institutionalized Ede has to confront all the ways that she has failed as Lily's advocate and protector. Charlie says that "[b]lame was the burden of all Ede's concern. She told me so on other occasions. She told me at length, when Lily died. *I didn't...* she would say. *I couldn't...* she said. *I tried...* And, inevitably: *I failed*" (Findley, 411). Even though Ede goes to see Lily every day during her incarceration, her guilt reaches further back in their lives. For years Ede had deluded herself into believing that marrying Frederick Wyatt had been in Lily's best interests, as well as her own. Although the decision did not cause Lily's illness, it divided Ede's loyalties in ways that undermined her ability to advocate for her daughter. As Lily declines, Ede is forced to acknowledge how the roles they have played in the Wyatt dynasty have compromised them all.

The biggest deceit of all, however, is perpetrated by David Henry in Edwards' *The Memory Keeper's Daughter*. Dr. Henry ostensibly lies to his wife about their baby's

death for the same reasons that Christopher's father lies to him about his mother being dead. Both men want to protect the people they love from being hurt. However, in both cases the people who lie are also trying to spare themselves the emotional difficulties that come with dealing with the truth. David "had wanted to spare [Norah], to protect her from loss and pain; he had not understood that loss would follow her regardless, as persistent and life-shaping as a stream of water. Nor had he anticipated his own grief, woven with the dark threads of his past. When he imagined the daughter he'd given away, it was his sister's face he saw" (Edwards 109). David's inability to accept responsibility for parenting a disabled child stems from the childhood trauma of watching his sister slowly die from a chronic heart ailment. However, in making his rash decision, David does not count on how important it would be for his wife to mourn the loss of a child she never saw, much less how the lie would undermine their marriage.

Norah is never allowed to see the body of the daughter she bore because Phoebe is actually alive. Without that contact, she is unable to properly grieve for her lost daughter. A year later, time has not eased her loss: "Norah still had the sense, inexplicably, of her daughter's presence, as if she might turn and see her on the stairs or standing outside on the lawn" (Edwards 79). She seems to be experiencing an almost instinctual awareness of her daughter's existence, even though she is not aware that the source of the growing estrangement between herself and her husband is the secret of Phoebe's life. Norah has no reason to suspect that her husband has lied about their daughter. It never occurs to her that Phoebe may possibly be alive and out there in the world. Yet, on some primal level she never recovers from the loss because she always senses Phoebe's presence.

David Henry eventually realizes that the lie about his daughter's death also touches his son, the twin he kept; and again he is astonished by how his instinct to protect

is shaped by his own childhood experiences of deprivation and loss. In the moment when he made the decision to give up his daughter, he was partly trying to protect his son so that:

Paul would not grow up, as David had, suffering the loss of his sister. He would not be forced to fend for himself because his sister couldn't.

This thought, and the force of its bitterness, shocked David. He wanted to believe he'd done the right thing when he handed his daughter to Caroline Gill. Or at least that he'd had the right reasons. But perhaps he had not. Perhaps it was not so much Paul he'd been protecting on that snowy night as some lost version of himself. (Edwards 113)

Over time, however, it becomes apparent that the ramifications of David's abandonment of his daughter do not spare his son, any more than they do his wife. Instead, Paul has grown up shaped by the family's loss, which affects his relationships with both parents, in different ways.

The choices family members make in Dismantlement literature must remove them from the pedestal occupied by characters like Mrs Rudge and Susan Dixon, in the Establishment phase. When Caroline finally confronts Norah with the truth about her daughter's life, she tells her how

"For years I believed in my own innocence... I believed I'd done the right thing. The institution was a terrible place. David hadn't seen it; he didn't know how bad it was. So I took Phoebe, and I raised her, and I fought many, many fights to get her an education and access to medical care. To make sure she would have a good life. It was easy to see myself as the hero. But I think I always knew, underneath, that my motives weren't entirely pure. I wanted a child and I didn't

have one. I was in love with David too, or thought I was... But when I saw the funeral announcement, I knew I had to take her. That I'd have to leave anyway, and I couldn't leave her behind." (Edwards 369)

In the end, there are no saints and no villains in these stories. All of the characters are more complex than simple categorization will allow, and they all make decisions that undermine their reliability as disinterested advocates for people who do not have the capacity or authority to speak for themselves.

In many cases the choices that caregivers make reinforce how much they have in common with the person that is dependent upon them. The Dismantlement novels portray how all the characters are susceptible to personal stress in trying to manage their relationships and responsibilities, showing that irrational behaviour is not exclusively associated with the characters who have a mental disability. In his confession, Christopher's father emphasizes how he and Christopher are alike when he tries to explain how he speared the neighbour's dog in a moment of irrational frustration and anger: "'So when she slams the door behind me the bugger's waiting for me. And... I know, I know. Maybe if I'd just given it a kick it would probably have backed off. But, shit, Christopher, when that red mist comes down... Christ, you know how it is. I mean, we're not that different, me and you'" (121-122). Christopher's Father reinforces their shared status as struggling and imperfect human beings when he concludes his confession by saying, "[w]e all make mistakes, Christopher. You, me, your mum, everyone. And sometimes they're really big mistakes. We're only human" (122). It is quite a departure to represent a disabled character in terms of how he is like another, 'normal' individual when disability has been more typically used to emphasize deviation from the norm.

Once all the lies are exposed, rebuilding the trust that Christopher counts upon to understand his world takes a long time. In fact, at the end of the narrative not all the relationships have been fully reconciled. Christopher's father tells him, "[y]ou have to learn to trust me... And I don't care how long it takes... If it's a minute one day and two minutes the next and three minutes the next and it takes years I don't care. Because this is important. This is more important than anything else" (Haddon 218). Not all the loose ends in Christopher's life and his relationships with and between his parents come together neatly in the end, as in a math equation or a puzzle.

While parents are most typically recognized as the 'natural' caregivers of children with mental disabilities, relationships between siblings have increasingly become a locus of investigation in disability studies and policy planning. Edwards' novel depicts how, following David's death and the revelation of Phoebe's existence, Norah and Paul can only speculate how their lives would have been different if David had not made the fateful decision to give Phoebe away. When Paul learns that his sister was passed off as dead because of her disability, he feels a number of different emotions:

anger at his father, and surprise, and sadness for what he'd lost. Worry, too; it was terrible to be concerned about this, but what if he had to take care of this sister who couldn't live on her own? How could he possibly do that? He'd never even met a retarded person, and he found that the images he had were all negative. None of them fit with the sweetly smiling girl in the photograph, and that was disconcerting too. (Edwards 383)

In fact, Paul's feelings are quite natural, given the vulnerability of many disabled people whose parents are no longer in a position to care for them. "For people with a developmental disability who live with parents or other relatives, families are the most



important providers of care. This includes not only parents, but also brothers and sisters who often play an increasingly important role as their parents age” (Government of Ontario, 2006, 17). However, not everyone who requires daily living supports has access to family supports.

For many other families, the personal care needs associated with the disability exceed their capacity to meet them. In his memoir about his relationship with his son, Walker, Ian Brown thinks about the futures of both his children:

I knew how much work Walker required, and how impossible it was for one or two or three or even four people to care for him adequately, to do everything that needed to be done, and still live productive, engaged lives in any other way.

Hayley’s life was her own; that, at least, was a gift we would give her. I refused to cover her with the thick, wet cloak of guilt under which many families of disabled children operate—a swamp of irrationality that has afflicted social thinking about disability for millennia... There are political factions and even entire governments that tap into this guilt and suggest that family is the only real solution to the problem of caring for the disabled.

But families, like disabilities, are not uniform or consistent. They’re anything but perfect. No one asks to join them, and more than half the time they don’t last. As a result—this was my thinking—the nuclear family is no model for a system to care for the severely disabled. (185)

The research on long-term outcomes for siblings of children with disabilities appears to be inconclusive. There is some evidence that the siblings of children who have mental disabilities may grow up to experience less emotional attachment to extended family members, even when caregiving responsibilities contribute to greater contact than in other

families (Taylor et al. 912). However, specifically in relation to siblings who have autism spectrum disorders (ASD), Ferraioli and Harris find that “[a]lthough being the sibling of a person with an ASD does have an impact on them that does not mean the influence is a psychologically harmful one” (50). Outcomes are likely to be affected by the nature and extent of impairment, by familial attitudes towards the disabled child, and by what supports are available for all members of the family. In *The Memory Keeper’s Daughter*, Paul is given explicit permission to lead his own life, allowing him the freedom to form a relationship with his sister that feels comfortable for them both (Edwards 397).

It is important to recognize that people with mental disabilities are often parents too (Montgomery et al. 21). *The Piano Man’s Daughter* is distinct from the other narratives considered in this sample in that it portrays a parent with a mental disability.<sup>46</sup> Lily is smart enough to capitalize on Frederick’s fear of social embarrassment when she returns from overseas with her illegitimate child. Charlie is three years old by then, and recalls that their

reception at Selby Street in 1914 was spectacular, to say the least. Lily had given no warning of our arrival, and the news of my existence having been so ill-received at my birth was no better received in my presence. We were immediately banished to a hotel.

...It was at this time that Lily paraded in front of the Selby Street house, pushing me in a pram I no longer needed—a picket line of two with a placard that read: WYATT PIANO COMPANY UNFAIR TO UNWED MOTHERS! (Findley 357)

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<sup>46</sup> Other contemporary literary examples of mothering and mental illness are Joan Clark’s (2005), *An Audience of Chairs* and Ursula Hegi’s (1994) *Stones from the River*.

With Ede acting as their emissary, Lily is able to extort enough money from Frederick to allow Charlie and her to live fairly comfortably in a series of hotels and upscale rooming houses, one after another, as her demons keep them moving. However, there are limits on Lily's freedom because Frederick ultimately has the power to have Lily committed to an institution. "It was a man's world then, in which only a man could have his legal way with such a decision" (Findley 358). Lily resists this authority, but she is sometimes a danger to herself and her son, especially when she experiences a mental break from reality and is compelled to suddenly pack up and escape the visions that torment her.<sup>47</sup>

Charlie's first lucid recollection of an escape is of an experience that occurred when he was four years old. He recalls his mother waking him in the middle of the night to tell him to pull his clothes on over his pajamas, and run. Eventually, Lily decides that it is safe for them to rest under a bridge where she makes a bed for them out of old leaves, where the snow cannot reach them. She removes his wet shoes, provides him with dry socks, and fits his slippers onto his feet:

Lying down beside me, she pulled her half of the blanket over her shoulders and, facing away from me, said: "good-night, Charlie. Sleep well..."

*Sleep well.*

I did not sleep at all. I didn't dare close my eyes. I kept thinking: *my mother is crazy. I am living with a mad person. What is going to happen next?*

Or the child equivalent of such thoughts. I had always accepted her, until that night, as being the way most mothers were—imperious, but trustworthy. Odd—but lovingly so. I had never felt imperilled by her madness. Now I was. (Findley 364)

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<sup>47</sup> Some people with mental disabilities have impairments that compromise their ability to parent to an extent that the safety and well-being of the child is at risk. However, people who cannot maintain custody of their children do not necessarily relinquish their self-identity as a parent. (Montgomery et al. 29)

He recalls other times when he had to be vigilant to prevent Lily from forgetting about him altogether: “Sometimes I would lose her. She would disappear. I constantly had to be on the alert—especially during our escapes, when Lily was already in traveling mode. She could say to me: *sit here, Charlie. Wait for me. I’m only going to the washroom...* Then she would not come back” (Findley 143-144). Still, Charlie is loyal to Lily for as long as he possibly can be. He is eight years old when his mother is finally hospitalized and transferred, against her wishes, to an asylum.

Along with the desperate escapes, fires, and seizures, Charlie recounts many happy memories with his mother. He tells the reader, directly: “Make no mistake of it—Lily knew happiness—Lily knew joy. We both knew heaven” (Findley 338). Yet it is the struggles and anxieties associated with loving Lily that make him determined not to ever have children of his own, even at the cost of his marriage. Like David Henry, Charlie has suffered from loving someone he could not save, and he makes the decision that his wife “will never have to bear the sorrow—or the burden—of giving birth to another Lily. No more Kilworth babies. None” (Findley 240). As Lily indicates, the last time Charlie sees her, the world just isn’t a safe place for them (Findley 4). Yet Lily also wants Charlie to marry and to promise to have a child. She tells him that she knows that he has a daughter out there waiting for him, and in the end Charlie does reconcile with the past by having enough faith in the future to have a daughter of his own.

All of the parents and children and siblings in these novels try to reconcile caregiving roles with their personal values and their need for self-realization within a policy context where assumptions about the costs associated with caring for a person who has a lifelong mental disability are often unrealistic. Similarly, the assumption that family members are reliable advocates who always know their child’s, parent’s, or

sibling's best interests is also unrealistic. However well family members believe that they know the person for whom they advocate, the informed perspective that comes with an intimate relationship needs to be balanced by an awareness that these are not disinterested parties. It is impossible for parents to see their child's future without also seeing their own.

### **Community Inclusion**

The Challenges and Opportunities Initiative was produced to advance the "government of Ontario's commitment to the encouragement of independence and self-direction for all Ontario citizens" (Government of Ontario, 1987, 3). It was an ambitious policy statement that made enthusiastic claims about the success of community living initiatives to that point, as well as very optimistic predictions about the capacity of people with mental disabilities to successfully integrate into a mainstream society ready and willing to accommodate. Most significantly, as a marker indicating transition from the Reform period to the Dismantlement phase of the Institutional Cycle, it is the first place where an official long-term goal of phasing out institutions altogether is articulated (3). Unfortunately, the document is very vague when it comes to evidence to support the claim that by the early 1980s a "better acceptance and understanding on the part of society regarding the needs of developmentally handicapped people in general had been achieved" (Government of Ontario, 1987, 8). In their novels, Findley, Edwards and Haddon suggest that social acceptance for people with mental disabilities is still by no means assured.

That Lily is marginalized from mainstream society is emphasized through Findley's evocation of the "madwoman in the attic," the *topos* that was made famous in

Brontë's *Jane Eyre* and revisited in Rhys' *Wide Sargasso Sea*. When Lily's "sickness" begins to emerge, her grandmother Eliza is the only one who knows that "in a dark room high in the attic, her own father's brother had been hidden from the world in her grandparents' house. Lovingly cared for—but publicly unacknowledged—he, too, had suffered from Lily's illness. Her condition" (Findley 98). Eliza decides that it is incumbent upon her to confide the life-story of her uncle John Fagan to Lily's mother, Ede. He was mad, had visions, and painted his prophecies of fire and death on the attic walls where "he spent the whole of his adult life. Hidden—but not in hiding. He was kept there by his parents—for *his safety's sake*. And because they were ashamed... which in itself is shaming. But..." (Findley 115; emphasis in original). Lily's mental disability is also enmeshed with a fascination with fire that emerges at the same time that Frederick commences the practice of confining her to the attic when the family entertains. Like Bertha Rochester, and like Uncle John Fagan, Lily Kilworth finally escapes her incarceration through fire (Findley 6).

As Findley draws upon the 'madwoman in the attic' topos, he makes the incarcerated lunatic more human than Brontë's original. In Eliza's recollection of her Uncle John Fagan, she says that he "... was childlike... childlike and simple", thereby linking both him and Lily, with the two dominant constructions of disability considered in the Establishment phase of the Cycle: the idiot and the lunatic. Still, the establishment of a hereditary dimension to Lily's emerging disability is a devastating revelation for Ede; one that compels her to hesitate before accepting Frederick Wyatt's marriage proposal. She wants a normal life for Lily, but she cannot be confident that Frederick will accept Lily and the ways that her mental disability may complicate their lives.

Once Lily joins her mother and stepfather, she is kept under close surveillance in their Rosedale home. Frederick, who owns a company that makes pianos for the drawing rooms of upper class families and concert halls, craves social respectability above all else. To achieve this end, shortly after their wedding Frederick has Ede commence

a thorough reading of *Our Deportment* by a man called John H. Young... Mister Young had collated a mass of instruction on the MANNERS, CONDUCT AND DRESS of what he called THE MOST REFINED SOCIETY—all set out in capital letters. Ede just laughed, but Frederick's insistence could not be brooked. He quizzed her on the book's contents day by day, until she finally consented to take it seriously. He also provided her with a copy of *Beeton's Book of Household Management* in order to acquaint her with a proper relationship with servants.

(Findley 173)

Ede is constrained by the expectations of the role she has assumed as the wife of an ambitious man. Her freedom of movement and expression are effectively impaired, and this extends to her ability to advocate for Lily.

This is made evident following Lily's seizure at a dinner party attended by people Frederick wants to impress. Immediately afterward he advises Ede that the Lily must be sent to her grandparents' farm because she is a "liability" to their "reputations" (Findley 207). Ede's protests are to no avail:

*Lily cannot harm our reputations. Only we can harm them.*

*The appearance of an idiot daughter... The presence of an idiot daughter... the fact of an idiot daughter...*

*She is not an idiot. Not an idiot.*

*She behaves like one.*

*A seizure is not behaviour—it's possession—being possessed.*

*I will not have it in my presence.* (Findley 208)

From Frederick's perspective, Lily is not fit for polite society and her presence threatens the family's place in the most exclusive social circles. Findley shows how Frederick commits a great deal of energy to conveying an image of domestic harmony and taste that is actually very false, as Lily and Ede are both shown to suffer in their prescribed roles.

Once Lily is allowed to return home, Frederick shows his wife how he has had the attic refurbished as a holding cell for Lily when the family entertains. Ede is devastated because she knows the terrors that the attic contains for her daughter, but Frederick will not be moved. Lily has gone to bed and is amazed to hear her mother and Frederick's voices above her room:

"Oh, God," Lily heard. "No—you mustn't do this. It will kill her."

"Don't be ridiculous," said Frederick—equally muffled, as if he were speaking through gauze. "Gain control of yourself. It isn't as if she has to *live* up here. It's nothing but a holding room."

*"A holding room? A holding room! Damn you!" ...*

"Oh—god—Fred—I cannot bear it. *Please.*"

This was said as words might be said in a dream or nightmare—spoken without a trace of inflection. Just the words, in a hollow space.

Ede, and then Frederick, crossed the ceiling and came down the still mysterious stairs and—after the briefest pause—a door was shut and a key was turned.

"Go to bed," said Frederick.

"Yes," said Ede. Broken. (Findley 227-228)



In the attic Lily's connection to Bertha Rochester is reinforced, as it is there that she begins to set her fires. Lily is only periodically incarcerated, but Frederick's actions limit her freedom to be herself, and she spends the rest of her life in defiance of socially prescribed norms for women of her time and place: she lives alone with her child conceived out of wedlock and she befriends strangers. Lily acts in response to the voices in her head, which carry more authority for her than culturally defined rules for personal conduct.

In Edwards' *The Memory Keeper's Daughter* and in Haddon's *The Curious Incident of the Dog in the Night-time*, social exclusion is manifested in different ways in the lives of Phoebe Gill and Christopher Boone. Edwards portrays Phoebe's unguarded affection for all people who show her any kindness. Her attachments are strong, genuine, and unreserved. This is stressful for her mother because Caroline does not want to suffocate Phoebe's affectionate nature. At the same time, however, she is also anxious to protect Phoebe from potential embarrassment and exploitation. Phoebe's vulnerability is evident when a man whom she meets on the bus invites her to his home. Phoebe does not go with him, but the episode prompts Caroline to remind her daughter that "[s]ometimes the world is dangerous. I think this man is dangerous" (Edwards 351). The experience draws attention to the risks to which Phoebe is exposed when she tries to navigate the world independently. Unfortunately, Caroline's anxiety about Phoebe's safety and what could have happened diminishes Phoebe's ability to recognize that she needed to go home and check with her mother before going with the man. Instead of celebrating Phoebe's competence, Caroline begins driving Phoebe to and from work in order to limit her contact with strangers.

Living a fully realized life inevitably involves taking risks, and when a person has a mental disability often others are called upon to determine the individual's capacity to manage those risks. In Edwards' novel, Phoebe eventually falls in love with a young man from the day program that she attends. Caroline struggles with her parental impulses to protect Phoebe and her cultural assumptions about the capacity of people with intellectual disabilities to form intimate attachments. As she watches her daughter's unabashed, "surging love" being reciprocated by Robert, Caroline asks herself, "[w]hy not? Wasn't such love rare enough in the world?" (Edwards 340). However, when Phoebe declares that she and Robert want to get married, Caroline tries to discourage the idea. After surprising Phoebe and Robert in an intimate embrace, Caroline finally tells her daughter that she cannot get married, have a home with Robert, and children of her own: "Phoebe's face was falling, tears were slipping down her cheeks. 'It's not fair,' she whispered. 'It's not fair,' Caroline agreed" (Edwards 346). In fact, there is no law preventing people with mental disabilities from marrying where they are capable of giving informed consent;<sup>48</sup> and many people with a developmental disability "are married and have children of their own" (Government of Ontario, 2006, 17). Jean Vanier asserts that "[o]ur communities are essentially places where people can serve and create, and, most importantly, where they can love as well as be loved" (Vanier 11). Generally, however, our cultural anxieties about sexuality, coupled with a protective impulse, have made it easier for caregivers and professionals to see people with mental disabilities as asexual.

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<sup>48</sup> The central character in Karen E. Bender's, *Like Normal People* (2001) has a comparable level of intellectual ability as Phoebe. Lena does marry and lives with her husband in a supported living housing complex.

When Paul is eventually reunited with his twin sister, and she tells him about Robert and her intention to marry him, Paul wonders “if it was true that Phoebe would get married. Then he felt bad for wondering this; why shouldn’t she get married, or do something else?” (Edwards 389). The right to make decisions for oneself and the obligation of guardians to protect can easily put people with mental disabilities in conflict with their caregivers and advocates, who are called upon to determine at what point the need to protect vulnerable people overwhelms their right to take risks. Throughout the three phases of the Institutional Cycle, all of the novels considered for analysis depict failed relationships and characters who make poor choices. These are human behaviours and experiences that are not confined to people who have a mental disability.

The presence of a communication impairment often further isolates people with mental disabilities and inhibits relationship building. In Haddon’s novel, Christopher explains that he cannot do “what is chatting, where people say things to each other which aren’t questions and answers aren’t connected” (Haddon 40). Due to their perceptual impairment, people with autism often have difficulty in comprehending what is going on around them and feeling secure in their environment. When the police question Christopher about why he is on his neighbour’s lawn in the middle of the night, cradling a dead poodle, he becomes overwhelmed by so much information coming at him all at once: “I rolled back onto the ground and pressed my forehead to the ground... and made the noise that father calls groaning. I make this noise when there is too much information coming into my head from the outside world” (Haddon 7). Without the ability to filter all the stimuli bombarding a person’s senses, one can find the world a terrifying place.

Furthermore, people who have disabilities that are not immediately apparent may experience a particular kind of intolerance from people who do not understand what they

are trying to communicate. In Christopher's case, the police officer is not immediately cognizant of Christopher's disability and how it makes him intolerant of strangers and especially of physical contact. As a result, the police officer inadvertently provokes Christopher's assault against him when he reaches out to lift him to his feet (Haddon 8). The situation is resolved only after Christopher's father arrives at the police station and the nature of Christopher's disability is explained.

Christopher needs to cope with his aversion to strangers when he runs away from home. In Findley's novel, however, Lily Kilworth considers that crowds are the best place to hide. Her first "escape" concludes when a man takes the seat beside her on the streetcar and begins masturbating. Thinking that he is having a seizure, Lily runs for help. In relaying the anecdote, Charlie remarks: "So much for escaping. The world of streets and trolley cars, which in time would become her permanent escape route, had offered her the promise of freedom only to bring her face to face with the fact that, in the streets, she would be pursued by demons other than her own" (Findley 268). Usually, however, Lily's instincts are good. It is never the strangers that she embraces who put her and Charlie in jeopardy.

From childhood, Lily rescues all kinds of things: from her Aunt Willa's discarded doll collection to toads and worms from the garden paths (Findley 192); Lily does not discriminate about what or who is worth saving. Charlie recalls one particularly poignant encounter when he and Lily are on the run. Sitting in a café in the middle of the night, Lily calls the young boy's attention to a man across the room: "The man had alarmed me. Frightened me. He seemed to have no face. His nose was gone and there was just a hole where his mouth should have been. What could have happened to him?" (Findley 144)

Eventually, Lily beckons Charlie to go with her to where the man is sitting. She startles the man by asking permission to sit with him:

Then, quite slowly so as not to alarm him, she reached across the table and took his hand in hers.

The man—I think unbelieving—looked down at the knot of their fingers—entwined. It was just as though someone had handed him a thousand dollar bill—or a diamond as big as a fist.

In his throat, he made a noise—the breath, not the shape of words....

No one spoke.

We sat that way for half an hour.

At first, I didn't understand why they went on holding hands for so long.

And then I did.

Lily was telling him that he was not alone. (Findley 145- 146)

Lily seeks out the lonely and disfigured, the social outcasts, because she is incredibly sensitive to their suffering.

Her sense of responsibility to humanity is consistent with the ideals that advocates of community living would have citizens embrace:

*Surely it is right and proper, Charlie, she said, that a person should help another person find his way home. It doesn't matter if you don't know who they are; it only matters that you get them there.*

“That’s our job, Charlie,” she said. “To get other people to the one safe place.”

It was not until after Lily’s death that I came anywhere near beginning to understand this. Her own *safe place*, which had seemed to be fire, was in fact other

people. Other beings. (Findley 324-325)

Lily's morality is sound. Unfortunately, it is not always safe to live with such a faith in the world. A theoretical perspective that understands disability in terms of personal deficiency constructs Lily's faith in strangers as a manifestation of impaired judgment. However, from the perspective of a social model of disability Lily's faith in strangers is problematic because society is not a safe place. It is not the individual who needs to be cured or controlled, but rather a society that is hostile and dangerous for people who feel responsible for helping another person "find his way home".

Not only must people with mental disabilities face social attitudes that hinder their inclusion in the community, they most often live in poverty, which is disabling in itself. Edwards' novel alludes to how poverty curtails active community participation (252). Dismantlement policy has emphasized the employment prospects for people with mental disabilities as a route to community integration, even though people with disabilities still experience much higher rates of unemployment and lower wages than the general public (Canadian Council on Social Development, 6; Titchkosky 51). This reality is particularly problematic because employment status has been indicated as a significant indicator of subjective well-being for people who have disabilities (Uppal 526). In addition, income supports such as the Ontario Disability Support Program (ODSP) provide minimal subsistence income. Residual income assistance policy reinforces the dominant social attitude that mental disability is an individual problem and a personal responsibility.<sup>49</sup>

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<sup>49</sup> In his long search for appropriate residential care for his son, Brown discusses how "[n]ew and even more exotic strains of guilt began to assail me. If Walker lived full-time in a good group setting, the cost would run at least \$200,000 a year. If he lived to the age of fifty, the total would be \$8 million. I didn't have \$8 million dollars, but there were eight million people in Ontario, the Canadian province where I lived. Was Walker worth a dollar a person?" (83-84)

The financial security of the characters in the Dismantlement novels is assured due to personal circumstances that are not typical of all people with mental disabilities. Edwards' novel indicates that Phoebe's long-term needs are looked after because David Henry had the means to establish a generous trust fund for the daughter whom he gave away at birth. In Findley's novel, Lily and Charlie are able to live comfortable, independent lives in a series of apartments and hotel suites in good neighbourhoods until Frederick's piano company fails and Ede cannot afford the fees for the private, transitional housing that helped keep Lily from the institution. In Haddon's novel, Christopher's future is uncertain but optimistic, as his extraordinary abilities in mathematics compensate somewhat for his impairments and may provide him with a university education his parents would otherwise have struggled to afford.

Ontario's Ministry of Community and Social Services (MCSS) has published a guide to assist people with "person-directed planning" in order to help facilitate the realization of life goals. Person-directed planning puts the "person with a disability at the heart of important decisions that affect their life" (Dingwall, Kemp & Fowke 4). It is an empowering objective; however, there are all kinds of reasons why people's plans may not be realized: limited resources, as well as a lack of cooperation from others who do not endorse the plan or do not perceive it as viable. Packaged as a tool to help foster independence and autonomy, such person-directed planning tools may actually work to absolve the community and its institutions from responsibility for taking an active role in realizing community integration. It is noteworthy, for example, that the case studies and planning examples given in the MCSS' guide identify the individual, family members, friends, neighbours, people from the individual's faith or church community, and people the same age as the individual as key consultants in planning (Dingwall, Kemp & Fowke

12). No mention is made of a role for government and its institutions in facilitating the realization of personal plans.

While planners and advocates debate appropriate parameters for social policy to support people with mental disabilities, an important indicator of community inclusion is an individual's ability to form relationships with people outside their immediate care circle. In Findley's *The Piano Man's Daughter*, Ede does not immediately send her daughter to school because she is afraid that once Lily's disability becomes exposed harassment or isolation must inevitably follow. Charlie explains that

In the back of her mind, where Lily was given the eternal promise of a normal life, Ede saw the years advancing as they had for herself. Grade school would one day offer Lily a formal education—and friends.

But not yet. Not now.

Ede knew the moment must come when Lily would rise from her desk in the classroom, spin out her chattering words and fall to the floor in a clatter of books and pencils, only to lie there helpless under the stare of her fellows—never to recover their esteem. Always thereafter, she would be their fool and their cretin—the butt of all their jokes and the object of their pity.

No.

Lily would not go to school. (Findley 181-182)

However, keeping Lily at home is even more isolating and prevents her from having opportunities to socialize and participate in the wider community. Ensnared as she has become in Frederick's middle-class, upwardly mobile ambitions that impose such narrow and rigid roles upon them all, Ede possibly underestimates the capacity of her community to accept Lily for who she is.



Certainly, when Lily does eventually go to school, she enjoys more freedom and a greater sense of ‘normalcy’ than she ever did enjoy in her confinement on Selby Street. She is able to form loyal friendships that support her and help to keep her safe when she loses touch with the everyday world. It is at boarding school that Lily meets the friends with whom she travels to attend Cambridge University in England. Having lived with Lily, they are familiar with her escapes and silences, and they care for her when she is “lost”(Findley 312). Lily succeeds to the extent that she does because she is able to build relationships with people whom she can count upon to care for her when she is not well.

Each of the novels considered in this sample emphasizes how vital are personal as well as financial resources to realizing community living objectives. Edwards chronicles Phoebe’s life-story until she is in her mid-twenties and at a place in her life where her family is still trying to figure out what her adult story will look like. She is on a waiting list for a group home:

a place where she could live with several other adults and a house parent. It seemed ideal in some ways—more independence and autonomy for Phoebe, at least a partial answer to her future—but the truth was that Caroline could not imagine Phoebe living apart from her. The waiting list for the residence had seemed very long when they applied, but in the last year Phoebe’s name had moved up steadily.

Soon Caroline would have to make a decision. (Edwards 343-344)

Phoebe’s circumstances do not seem to reflect the reality of the supported living infrastructure in Ontario where waiting lists are very long, especially for people who are as ‘high functioning’ as Phoebe, and who already have a strong personal support system. For example, when Ian Brown was looking for a supported living space for his son in

Canada's largest city he was told that the typical applicant was a forty year-old with parents who were themselves looking for long-term care living arrangements (82).

While Findley and Edwards portray mothers who sometimes diminish their daughters' abilities in order to protect their children and maintain influence over their lives, in Haddon's novel Christopher Boone's father tries to actively support his son's ambitions by defending his right to take the necessary entrance exams for university (44-45). Even though Christopher has little capacity to understand things that are not real, he is a boy who is still able to imagine growing up to be an astronaut, despite the taunts of an older boy who tells him: "I would only ever get a job collecting supermarket trollies or cleaning out donkey shit at an animal sanctuary and [that] they didn't let spazzers drive rockets that cost billions of pounds" (Haddon 25). Even though Christopher does concede that he may never become an astronaut, he has thought carefully about one day leaving home and moving to another town to attend university:

Then, when I've got a degree in maths, or physics, or maths and physics, I will be able to get a job and earn lots of money and I will be able to pay someone who can look after me and cook my meals and wash my clothes, or I will get a lady to marry me and be my wife and she can look after me so I can have company and not be on my own. (Haddon 45)

Despite his losses and his impairments, Christopher has abilities that place him outside of the mainstream of the population diagnosed with autism spectrum disorders. With the necessary supports he may realize his goals.

For most people with severe mental disabilities, however, the prospects for community inclusion through employment do not seem to be improving. The optimism of contemporary planning policy at times almost glosses over the reality that having a

severe mental disability inevitably places limits on the degree of independence that a person can achieve. For instance, the Challenges and Opportunities Initiative proposed maximizing employment opportunities for people “disadvantaged by developmental handicaps” by pursuing the following objectives:

- placement of developmentally handicapped people in competitive situations;
- development of on-the-job training opportunities with appropriate supports;
- development and implementation of supported employment;
- refinement and promotion of the Affirmative Businesses;
- implementation of an equitable and objective wage policy. (Government of Ontario, 1987, 28)

There is little evidence that any these objectives has ever been achieved. In fact, subsequent provincial administrations have cut funding to the developmental services sector, even as the deinstitutionalization process was accelerated (Pedlar & Hutchison 639-640). As a result, many of the resources invested in supported work opportunities were eliminated, as community agencies were required to focus their depleted resources on providing accommodation and basic programming (“Unkind Cut for Disabled”, para. 2-4).

As novelists begin to portray mentally disabled characters as more complex individuals, these characters more often become the protagonists in their own stories rather than bit players in other people’s narratives. There are cultural assumptions about people with mental illness, with autism, with Down syndrome and every other mental disability diagnosis that is affixed to people. However, when Phoebe’s mother looks at her daughter, she sees “the thing that couldn’t be measured, couldn’t be quantified or

even explained: Phoebe was herself alone. You could not, finally, categorize a human being. You could not presume to know what life was or what it might hold” (Edwards 168). Findley and Haddon also create characters who transcend stereotypes about mental disability in novels that depict the challenges of trying to determine the right balance of personal and structural supports that are necessary for people with mental disabilities to live safely in society and experience community inclusion in a meaningful way.

### **Re-conceptualizing the Institution**

Findley’s, *The Piano Man’s Daughter*, is a contemporary novel that depicts the asylum as it existed in 1918. Charlie describes “Lily’s first asylum—the one on Queen Street in Toronto—[as] appalling. The buildings, for all their windows, gave an impression of darkness. Inside, there was always someone screaming” (Findley 435). In his detailed historical study of patient life at this institution at this time, Geoffrey Reaume recounts the following evidence from a patient file:

In 1915, May K., the sister of patient Anne D., wrote that on a previous visit two years before her sister was “in a room not fit for an animal to be confined in—a cot bed with a mattress on it not fit for any human being to sleep on, the sole furniture without even a change of clothing”. ...For most of those on the better wards, hospital life was not one of comfort even by the standards of their own time, and there were significant variations in the environment of paying wards. ...For the majority of inmates who had no money to improve their surroundings—the men and women on the public wards—their physical environment at 999 Queen Street West was cold, crude, and harsh. (11)

Returning to Findley's novel, Charlie recalls that during Lily's initial weeks at 999 Queen Street "[p]ermission for visits was very hard to come by.... Observation privileges, on the other hand, could be arranged... There were rooms where you could not be seen, but from which you could observe your wards and charges at play—or at work, as the case might be. Also when sedated. Sometimes seated on the floor" (Findley 435). Lily is committed when she is in an active psychotic and suicidal state. As a result she is put in isolation, under close surveillance.

Reaume further finds that "there were as many circumstances leading to confinement as there were patients. The asylum itself was viewed with genuine fear and loathing by some, while for others who felt they had nowhere else to turn it was perceived as a last refuge" (24). In some ways, present-day institutional reality for people experiencing active psychosis is not very different from what Findley and Reaume describe: Visiting is very restricted, screaming and other symptoms of distress are not unusual behaviours for people experiencing active psychoses or suffering the effects of forced confinement in an alienating environment; police come and go on a regular basis, and people who are free to leave their rooms may be disoriented from the effects of very strong medication.<sup>50</sup> The final report of the Kirby Commission quotes from the experiences of several participants who have been patients on psychiatric wards. Jennifer Chamber's testimony, for example, speaks to some of the most disturbing aspects of institutional care depicted in novels across the Institutional Cycle:

To speak from my personal experience, being on a psychiatric ward was one of the

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<sup>50</sup> In *Hurry Down Sunshine* (2008) Michael Greenberg gives his first-person narrative about his daughter's diagnosis and treatment for bi-polar disorder. He describes the psychiatric facilities where Sally receives treatment that includes isolation units, locked wards and expressions of extreme distress and euphoria that are common for people in an active psychotic or manic state.

most traumatic experiences of my life. The things that happen on a psychiatric ward taken in any other context would be seen as devastating. People being locked in tiny rooms they cannot leave, tied to a bed and injected with chemicals against their will are clearly traumatic experiences. Being told that it is all right because they are in a hospital is really a departure from reality. (In Kirby 4)

The nightmare vision of the mental hospital is one that persists across all phases of the Institutional Cycle in fiction and nonfiction narratives, and it has provided strong impetus for the de-institutionalization movement. However, it is important to distinguish between those supports that accommodate the day-to-day needs of people who have a chronic disability and the intensive intervention that may be required for someone experiencing an acute crisis. Furthermore, if necessary daily living supports such as secure housing and adequate income were accessible for all people, the incidence of acute mental health crises could be substantially diminished (Kirby 6).

Eventually Lily is transferred to a private facility that Charlie describes as a kind of home for the mentally ill. Lily's experience reaffirms research that finds that the experience of institutional care varied in accordance to the patient's ability to purchase a degree of comfort and privacy:

Her second asylum was for *private patients only*—as if all patients don't want privacy. On the other hand, this particular institution—to which my mother was committed on three separate occasions—was extremely well run and set in the midst of a terraced garden. The buildings were part of an estate in North Rosedale that had been left by its owner especially *for the care of madwomen*... The late owner's daughter had been schizophrenic and had committed suicide. (Findley 437 emphasis in original)

Lily stays there until her family can no longer afford to pay the costs, which occurs after Frederick dies and the Wyatt Piano company fails (Findley 442).

The existence of such a facility speaks to a gap in contemporary policy in terms of provision of a range of housing services that are flexible enough to support a diverse population comprised of individuals who may have different needs at different times. Furthermore, supported living facilities that do exist do not always live up to the vision of community care articulated in Reform-era planning that recommended that residential facilities be located in the midst of the community and accessible through public transportation (Welch 4; Williston 74). In fact, group homes have tended to be constructed on the fringes of communities where real estate is cheaper and there are fewer restrictive zoning bylaws.<sup>51</sup> The Kirby report recommends the establishment of a Mental Health Housing Initiative (118-123) that could be implemented with a spectrum of services to meet the needs of all people who are insecurely housed as a result of poverty and mental disability.

Contemporary novels that are set in subsequent phases of the Institutional Cycle portray how the very limited range of community services available for people with mental disabilities continues to undermine the potential for community inclusion for many. Edwards' novel depicts a doctor who, in 1964, sees the institution as the best way to protect his family from what he perceives as the inevitable grief of living with mental disability. This belief prompts him to direct his nurse, Caroline Gill, to immediately deliver his newborn daughter to an institutional facility, while he convinces his wife that their daughter did not survive her birth. Caroline makes the journey, but ultimately acts

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<sup>51</sup> The *Toronto Star* published a report (24 April 2010) revealing a number of jurisdictions in Ontario (Toronto, Kitchener, Smiths Falls and Sarnia) that still had "restrictive zoning bylaws governing where group homes for people with disabilities could be located" (para. 6).

upon her own moral impulse in deciding not to leave the child. Edwards does a good job reconstructing the image of the “home for the feeble-minded” (Edwards 31) through Caroline’s eyes, as it would have looked in the 1960s:<sup>52</sup>

across a mile of pale hills, she glimpsed the building, built of red brick at the turn of the century, with two incongruous low-slung modern wings. It disappeared, now and again, as she followed the curves and dips of the country road, and then was suddenly before her.

She pulled into the circular driveway. Up close, the old house was in a state of mild disrepair. Paint was peeling on the wood trim and on the third floor a window had been boarded up, broken panes backed with plywood. (24)

The “modern wings” suggest the constant expansion that the institutional system in North America had been experiencing since its inception, and was only beginning to subside around the time that this scene is set.

The antiquity of the place is impressed upon Caroline, suggesting a response to disability that is from another era: “She stood and walked to the windows, the floorboards shifting and creaking beneath the worn carpet. Velvet drapes brushed the floor, remnants from the far-flung time when this place had been an elegant estate. She touched the edge of the sheer curtains beneath; yellow, brittle they billowed dust” (Edwards 28). Going deeper into the facility, she experiences an incongruence of past and present, held together by a pervasive sense of general neglect, as she passes “several doors, glimpsing moments of people’s lives, the images suspended like photographs”

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<sup>52</sup> The description given resembles Greenberg’s (1964) representation of the Blau family’s first impression of the mental hospital in *I Never Promised You a Rose Garden*, as they drive toward a redbrick, somewhat run-down, Victorian building out in the country (ch. 1).



(Edwards 29). Caroline's walk through the institution is described as a series of still frames. The strongest impression is made upon her by the image of

a young woman wearing a white cotton slip sat on the edge of a bed, her hands folded lightly in her lap, her head bent. Another woman, a nurse, stood behind her, silver scissors flashing. Hair cascaded darkly onto the white sheets, revealing the woman's bare neck: narrow, graceful, pale. Caroline paused in the doorway.

"She's cold," she heard herself saying, causing both women to look up.

The woman on the bed had large eyes, darkly luminous in her face. Her hair, once quite long, now jutted raggedly at the level of her chin.

"Yes," the nurse said, and reached to brush some hair off the woman's shoulder; it drifted through the dull light and settled on the sheets, the speckled grey linoleum. "But it had to be done." (Edwards 29)

It is a curious picture, as much for what it implies as what it depicts. The young woman is presented in a vulnerable way, with her head bowed and her neck exposed. The image of submissive resignation recalls a scene from Brontë's *Jane Eyre* in which Helen Burns is beaten with a switch on the back of her neck for not keeping herself neat (Brontë ch.

VI).<sup>53</sup> The hair is being hacked off with no consideration for appearance, the implication being that the way the young woman looked really is of no consequence. The young woman's deference to the procedure suggests resignation and no reason to care for herself. Finally: "it had to be done". When Lily is institutionalized they "cut her hair off for fear she would use it to strangle herself. Women had done that—wound their long

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<sup>53</sup> "...Burns immediately left the class, and, going, into the small inner room where the books were kept, returned in half a minute, carrying in her hand a bundle of twigs tied together at one end. This ominous tool she presented to Miss Scatterd with a respectful courtesy; then she quietly, and without being told, unloosed her pinafore, and the teacher instantly and sharply inflicted on her neck a dozen strokes with the bunch of twigs. Not a tear rose from Burns' eye; and... not a feature of her pensive face altered its ordinary expression." (Brontë 64-65)

braids of hair around their necks and hanged themselves. Now—all hair was cut. A matter of course. That and trimmed fingernails” (Findley 436). Perhaps the woman Caroline observes just couldn’t keep her hair neat. Possibly it was often in her food; maybe the woman pulled at it when in distress. It is the submissiveness and the absence of a personal narrative to explain why the procedure “had to be done” that makes the strongest impression in this scene.<sup>54</sup>

This image prompts Caroline to take the baby back to her home in the belief that, given time to reconsider, Dr. Henry will change his mind about keeping Phoebe. However, she is made aware of David’s deception when she reads a notice in the newspaper for a memorial service for the baby who is very much alive. She immediately arranges to meet him and urges him to recant. When Caroline explains how she could not bring herself to leave the child at the institution, as David directed, she is relieved when he admits that he had never actually been to the place: “‘It came highly recommended, that was all. I’ve sent other people there, in the past. I’ve heard nothing negative’” (Edwards 64). Of course, there is ample historical evidence of all kinds of deprivation and abuse that has been allowed to occur over many years in institutional facilities where residents were not aware of their rights, or were not able to express them.<sup>55</sup> However, he still insists that he has tried to do what was in everyone’s best interests, and he is not

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<sup>54</sup> In her memoir of her mother, and her slow death by dementia, Heather Menzies (2009) generally speaks positively about the care that her mother received in the long-term care facility where she was eventually transferred. However, she shares one angry recollection of arriving to visit her mother one day to find that her hair had been cut: “I turned on my heel and went straight to the office. Turns out, the cutting hadn’t been done by the resident hairdresser, but by one of the personal-care attendants assigned to help Mum get washed and brushed and dressed in the morning. Something about Mum’s hair getting in the way. I was furious. This was my mother. This was her hair, a hairdo that marked her as much as her name. It was her identity, not something to be done away with for someone else’s convenience!” (131)

<sup>55</sup> In her novel, *Icy Sparks* (1998), Gwyn Hyman Rubio describes incidents of compassionate care and also abuse in a mental hospital, also in Kentucky, where the eponymous heroine is sent in the mid-1950s to be treated for what is diagnosed today as Tourette Syndrome.

pleased that his nurse failed to follow through with his request: ““I believe the home in Louisville is the right place for this child. I don’t make the decision lightly. She will need medical care she cannot get elsewhere”” (Edwards 65). David adheres to a medical model of disability that perceives people with disabilities as inevitably afflicted, medically fragile, and unable to thrive in the wider world.

Even a year later, once he recognizes how his decision to send his newborn daughter to an institution has created a lie that is undermining his relationship with his wife, and causing her inconsolable pain, David still is unable to take full responsibility for the unresolved grief: “David felt a sense of panic, almost vertigo, at all he didn’t know; at all he knew and couldn’t mend. And anger: he felt that too, suddenly, in a great rush. At himself, but also at Caroline, who had not done what he’d asked, who had made an impossible situation even worse” (Edwards 122). This need to control is dominant in David, so it makes sense that he embraces an institutional response to disability where order is imposed upon abnormality that cannot otherwise be solved.

Policy and literary analysis both indicate that families who are bringing up children who have mental disabilities often experience a lot of stress. In Haddon’s novel, the burden of responsibility for Christopher’s care takes a high personal toll, and there are limits to the Boones’ ability to constantly anticipate Christopher’s needs and make his environment functional for them all. As a result, Christopher’s “behavioural problems” provoke problematic behaviours and verbal outbursts in others. He says that:

Sometimes these things would make Mother and Father really angry and they would shout at me or they would shout at each other. Sometimes Father would say, “Christopher, if you do not behave I swear I shall knock the living daylights out of you,” or Mother would say, “Jesus, Christopher, I am seriously considering putting

you in a home,” or Mother would say, “You are going to drive me into an early grave.” (Haddon 47-48)

Eventually, Christopher’s mother leaves the marriage, which is not surprising given the high rates of breakdown in marriages where parents are raising a child with severe disabilities. Brown talks about the toll that caring for their disabled son took on his own marriage, noting that “[e]stimates of the number of marriages that fail due to caring for a disabled child range from 60 to 80 percent” (97). Brown suggests that in their case, part of what held his wife and him together was the simple reality that there was no other way to care for their son unless they did it together.

The swing of the policy pendulum from a place where institutionalization was considered as the most appropriate option for severely disabled children and their families, to a position advocating family as optimal caregivers has been dramatic and in some cases devastating. In 2005 the Ombudsman of Ontario published a report that exposed a policy system that sometimes required parents with children who have complex needs to surrender custody of their children in order to attain relief from an intolerable situation for their children and themselves. He concludes that

[t]here are families in crisis in Ontario. There may be as many as 100-150... families who, out of desperation, have been forced to give up parental rights in order to get their children the residential care they require. In most of these cases there was no need to strip those parents of parental rights because they are capable and loving parents, entirely able to act responsibly. These people are being forced by the weight of the intolerable burden of caring for their children with special needs, to sign agreements acknowledging falsely that they are unable to care for those children, or even to engage in what for most parents would be the ultimate act

of betrayal—to declare formally, for the public record, that they are abandoning their children... These families are struggling to cope with children with special needs at home, even though professionals have said that in the interests of the family and of those children that the children need to be placed in residential facilities. Yet, these parents struggle with intolerable home lives, knowing that their children's names are placed on a waiting list, sometimes for years. (Marin 40)

Marin's findings are consistent with the experience of the Brown family who waited for seven years to get a placement for their son (Brown 78), even though he is medically fragile, requires tube feeding, engages in self-injurious behaviours, is incontinent and nonverbal. Despite the fact that they were a two-income, professional, middle-class family, Brown admits that there "was nowhere we could afford to put him, and there was nowhere to put him anyway" (69). As government policy has have moved away from facilitating the institutionalization all children with mental disabilities, families who would once have had very little input into the lives of their mentally disabled children are now stranded without necessary supports that long-term care facilities once provided.

As the prevalence of long-term care for children with disabilities has been substantially reduced, although not altogether eliminated, a lot of the institutional debate in the Dismantlement phase has shifted from residential facilities to the school system. Lily, Christopher, and Phoebe all eventually go to school. However, Caroline has to fight for Phoebe's right to attend public school by participating in legal action, alongside other

parents with children who have learning disabilities.<sup>56</sup> The presentation of their case to members of the local school board prompts the following exchange:

“We on the board appreciate everything you say, and we appreciate the commitment and devotion of these parents. But these children are mentally retarded; that’s the bottom line. Their accomplishments, significant though they may be, have taken place within a protected environment, with teachers capable of giving extra, perhaps undivided, attention. That seems a very significant point.”

“Mentally retarded is a pejorative term,” Ron Stone replied evenly.

“These children are delayed, yes, no one’s questioning that. But they are *not* stupid. No one in this room knows what they can achieve. The best hope for their growth and development, as for all children, is an educational environment without predetermined limits. We only ask for equity today.” (Edwards 161-162 emphasis in original)

This episode in the novel is set in 1970, and Edwards is not historically accurate in having the parents’ lawyer object that the term “mentally retarded” is pejorative. In fact, it is the designation typically used in Ontario policy planning until late in the 1970s. Both Williston (1971) and Welch (1973), for example, wrote influential policy reports for the Government of Ontario regarding the provision of community supports for people who are mentally retarded.

At Caroline’s meeting with the school board, another trustee on the panel acknowledges the lawyer’s appeal to equity by making reference to a lack of resources:

“To be equitable, we would have to accept them all, a flood of retarded individuals that

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<sup>56</sup> This theme of parents (especially mothers) advocating for their children to lead ‘normal’ lives is pervasive in all phases of the Institutional Cycles. Another literary example, in the Dismantlement phase, is Karen E. Bender’s (2000) *Like Normal People*.

would overwhelm the system” (Edwards 162). This is also an enduring argument used to rationalize caps on social welfare services for people who cannot adapt to mainstream standards and expectations. The case for imposing caps on certain services has been made by the Government of Ontario in recent years to limit funding for intensive behavioural intervention (IBI) services for children who have complex disabilities, such as autism, even though “Bill 82 ensured that all exceptional school-age children in Ontario would have available, by 1985, special education services and programs appropriate to their individual needs without payment of fees by parents or guardians” (Government of Ontario, 1987, 7). A class action suit was launched against the Government of Ontario for refusing to fund IBI beyond the age of six years. The parents won a lower court decision in April 2005, when Judge Kitley ruled that

“...the age cutoff reflects and reinforces the stereotype that children with autism over age 6 are virtually unredeemable...The absence of ABA/IBI means that children with autism are excluded from the opportunity to access learning with the consequential deprivation of skills, the likelihood of isolation from society and the loss of the ability to exercise the rights and freedoms to which all Canadians are entitled.” (In Makin, 8 July 2006, A6)

In Edwards’ novel, Caroline does win her battle to obtain an education for Phoebe; however, social welfare advocates realize that few social justice battles are ever won outright, and ground that is gained can always be lost again.<sup>57</sup> Indeed, the Province

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<sup>57</sup> Returning, for example, to the issue of parents having to relinquish custody of their children in order to obtain necessary long-term care supports, the Ministry of Children’s Services pledged to change this practice following the release of Marin’s (2005) report. However, stories of parents caught in this same dilemma continue to come up. Rob Ferguson documented the Comisso family’s situation on 1 May 2008, and Tanya Talaga reported on the Gallinger family’s case on 20 July 2009, both in the *Toronto Star*. Talaga reports that critics argue that “the Liberal government has failed to implement changes advocated by

successfully appealed Kitley's ruling, which was overturned in July 2006 by the Supreme Court.<sup>58</sup>

In Findley's novel, Lily is finally sent away to a private boarding school following a series of serious fits that concludes with her setting every item of her young brother's clothing on fire in bitter revenge for his deliberate destruction of the ant colonies that she had studied and nurtured. The event also occasions what her son, Charlie, refers to as the first of Lily's escapes. "This was not, as they came to be, an escape from her demons, but only from Frederick and the house on Selby Street. Having already packed her suitcase, she simply left" (Findley 264). However, Lily cannot escape Frederick's judgment and she is sent to a school "forty-eight miles away in a field north of Newmarket—almost all the way to Lake Simcoe. The dormitories and classrooms were housed in a large stone building that once had been a convent. It was called St. Mary-Margaret and it prided itself on its mastery of difficult students" (Findley 269). Upon moving Lily to her new residence, Ede flinches at the Director's philosophy of rule "“with an iron hand... in a velvet glove”", but she also is "resigned to the fact that strictures were required if Lily was to be controlled" (Findley 270). However, despite the foreboding introduction to the new regimen, Lily enjoys more liberty at boarding school than she experienced living in the Wyatt family home.

In *The Curious Incident of the Dog in the Night-time*, Haddon portrays his hero living in the community, yet Christopher Boone is still segregated from 'normal' children by attending a school for children with exceptional needs. He describes his classmates in the following terms:

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Marin four years ago to ensure legal protection against loss of custody, and money for the children's care. Instead, ad hoc solutions and funding are scraped together as the need arises—with mixed results" (A1).

<sup>58</sup> A compilation of media reporting on this decision is available at <http://dawn.thot.net/autism-ruling5.html>



All the children at my school are stupid. Except that I'm not meant to call them stupid, even though this what they are. I'm meant to say that they have learning difficulties or that they have special needs. But this is stupid because everyone has learning difficulties because learning to speak French or understanding relativity is difficult and also everyone has special needs, like Father, who has to carry a little packet of artificial sweetening tablets around with him to put in his coffee to stop him from getting fat, or Mrs. Peters, who wears a beige-colored hearing aid, or Siobahn, who has glasses so thick that they give you a headache if you borrow them, and none of these people are Special Needs, even if they have special needs.

(Haddon 43-44)

Christopher does not resent his segregation from the mainstream as much as he resents how language is manipulated to avoid acknowledging the deliberate policy of separating children with learning disabilities from the general population of people who all have “special needs”.<sup>59</sup>

In many jurisdictions, segregated schools have become a controversial approach to education. For the past several years, in Ontario, an integrated curriculum even for students with the most severe mental disabilities has been promoted as the most inclusive, and therefore appropriate, option. Parents, however, do not unanimously endorse this policy. Brown shares his own experience:

Walker begins to attend Beverley Junior Public School—a famous local institution dedicated entirely to intellectually disabled children, where the ratio of students to

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<sup>59</sup> Simi Linton interrogates the meaning of “special education” and suggests that “[l]abelling the education and its recipients [as] special may have been a deliberate attempt to confer legitimacy on the educational practice and to prop up a discarded group. It is also important to consider the unconscious feelings that such a strategy may mask. It is my feeling that the nation in general responds to disabled people with great ambivalence. Whatever antipathy or disdain is felt is in competition with feelings of empathy, guilt and identification.” (164)

teachers is a mere three-to-one. The school is a bright, airy space designed for children who can't see out of normal windows or walk easily through a standard door. Its effect on Walker's confidence is instantaneous: within a month he progresses from needing to be carried from room to room at school to walking on his own. But within a year, the provincial government announces its intention to close the school. The school is only for the disabled—a 'segregated' facility, in the parlance of disability education—and doesn't conform to the province's policy of supporting (much cheaper) 'inclusive' schools, where, theoretically, the disabled learn alongside the abled, and each gets used to the other. Inclusive schools are often excellent, and much preferred by a certain generation and political ilk of educators. But even those educators will admit integration isn't for everyone, that dedicated facilities can be more helpful for children as delayed as Walker. (87)

Public protest eventually succeeded at keeping this school open, but Brown concludes that "the government's priorities are clear: the disabled don't vote, and so don't deserve much individual attention. They don't fit the formula—any formula" (88).<sup>60</sup> Segregated education is perceived to reinforce marginalization in the wider community and emphasize difference instead of what children have in common. However, Brown shares the opinion of some other parents and disability theorists who believe that some children have more intensive learning needs that are just not being addressed in a mainstream system.<sup>61</sup>

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<sup>60</sup> In fact, people with disabilities have had the legal right to vote in Ontario elections since 1985, and federally since 1988. (See CBC Digital Archives, 16 Nov. 1988; Prince 2004). Brown is making the point that people with disabilities do not comprise a voting constituency of sufficient size to influence political agendas.

<sup>61</sup> In a *Toronto Star* article (23 May 2010) Laurie Monsebraaten profiles Heydon Park Secondary School, which was originally established in 1923 as a public vocational school for girls. Today, "[a]bout one-third of the school's 200 students have mild intellectual disabilities, including a dozen girls who have Down

In Haddon's novel, Christopher's story also demonstrates that a facility dedicated to educating people with disabilities is not necessarily more progressive in its administration, or inclined to deliver a flexible curriculum, according to each student's individual abilities. Christopher recounts how his school principal, "Mrs. Gascoyne... didn't want to treat me differently from everyone else in the school because everyone would want to be treated differently and it would set a precedent" (Haddon 44). When the issue of Christopher taking the university qualification math exam is raised, Mrs. Gascoyne suggests that "she and Father should talk about this at some later point on their own" (Haddon 44). In response, Christopher's Father insists upon his son's right to at least bear witness to decisions that affect his ability to realize his own goals. Christopher recounts that his father asked "whether she wanted to say things she was embarrassed to say in front of me, and she said no, so he said, 'Say them now, then'" (Haddon 45). In this instance, Christopher's Father wins the right for Christopher to write the necessary entrance exams because he refuses to engage in subterfuge and accept excuses for denying Christopher's right to participate in decisions affecting his own future. This episode also demonstrates how even when people with mental disabilities have a voice, their narratives almost always still need to be supported by an advocate.

In Findley's novel, Lily Kilworth's story begins and ends in a mental hospital, where she never feels safe "[i]n spite of its being an asylum" (Findley 4). Lily is finally committed to an institution following her breakdown, which occurs when she learns that her fiancé has been killed in World War I, on the final day of fighting (Findley 420). She

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syndrome. Autism, Asperger's syndrome and fetal alcohol syndrome are other common conditions. The rest of the student body is made up of girls with average intelligence who are considered 'high risk' due to learning disabilities, mental health issues or behaviour problems. Many come from troubled families and tough neighbourhoods. Three are pregnant, a dozen are Children's Aid Society wards, and some have suffered sexual or emotional abuse and been exposed to violence and even murder in their homes. Many would be bullied, ostracized or just lost in a regular high school—if they attended at all..." (para. 17-19)

is hospitalized following a dramatic suicide attempt, by fire, at the movie theatre that had been her haven from the world:

In the hospital, she fought the nurses and the doctors who were trying to save her life. She fought them so effectively, somebody had to knock her out. When her stomach had been induced to give up its contents and a shot had been administered to calm her down, she still persisted in her kicking and shouting until, at last, she was captured and restrained and put into a strait-jacket. (Findley 427)

At the Queen Street Lunatic Asylum, Lily is confined at first in a padded cell before being kept under close observation in a ward with others who were considered to be dangerous to themselves or others. Charlie is unable to see his mother for several months, until she is stabilized.

At one point he explains his role in relation to his mother's illness in the following terms: "I was never Lily's keeper. I was only ever her child—and, on occasion, her guardian and, on occasion, her victim and, on occasion, her accomplice. But I was never her keeper. The *Keeper* in Lily's life was fire. Her jail was her illness, and its key was in a box of matches" (Findley 255). Lily does eventually die by fire in the asylum. Given the historical evidence cited by Berton, Reaume, Simmons, and Williston about the structural hazards of institutional facilities, the circumstances of Lily's death, and those who perish with her, seem very plausible:

There will always be some debate about whether or not she started it. Smoking was allowed in the Asylum. Smoking, but not matches. Not lighters. When a patient wanted a cigarette, she had to go and ask the nurses or the orderlies for a light.

Still, Lily was Lily, and she had her own ways of coming by matches. ...

Twenty inmates perished. Most of them were caught in a stairwell whose door somehow got locked behind them. At the bottom, there was thick wire meshing—and no way through. (Findley 43)

From the moment that Findley invokes the legacy of the ‘madwoman in the attic’, it is anticipated that Lily must die by fire. However, he also builds upon the archetype made famous by Charlotte Brontë in the Establishment phase of the Cycle, and made human by Jean Rhys in the Reform period. Findley’s ‘madwoman in the attic’ wins more battles, has more friendships, knows more love, and lives a richer life than either of her predecessors. Within or outside of the institution, all the authors in this sample tell stories of lives constrained by policies of segregation that emphasize impairments over abilities, as the Dismantlement phase continues to struggle to reconcile the limitations of the community with the limitations of the individual.

## **CHAPTER 9- Findings**

### **Learning from a Comparative Examination of Literary and Social Policy Discourses**

The review of the novels and policy documents that comprise the data sample for this research reveals that mental disability has typically been perceived in a much more limiting way in policy than it has been portrayed in literature, notwithstanding Parsons' assertion that "[o]ver the years, governments have been guided by social values of the time and the public's perception of moral obligation versus actual legal responsibility" (13) for people with mental disabilities. Policy planners have typically regarded idiocy and lunacy, mental retardation, or disability as conditions to be managed while novels portray how policy actually plays out in people's lives. The ways that mental disability is represented in novels often challenges prevailing policy assumptions about rights and the roles available to people. At the same time, cultural constructions of mental disability and the potential storylines available to them are influenced, and sometimes even determined by policy priorities, over time.

Table 6 identifies key themes and dominant perspectives that were prevalent throughout the Institutional Cycle and that informed responses to the research questions articulated in the methodology. The findings of the research identify several relationships between the novels and policy texts that influence how the life stories of people with mental disabilities are constructed in policy designed to cure, control, or accommodate individual needs and rights. Disjunctions between literary and policy discourses may be read as locations in the Institutional Cycle where social policy and cultural

Table 6

## DISCOURSE THEMES ACROSS THE INSTITUTIONAL CYCLE

	LITERARY NARRATIVES	POLICY DISCOURSE
<b>ESTABLISHMENT PHASE</b>		
<b>How Their Stories are Told</b>	<ul style="list-style-type: none"> <li>The life narratives of nonverbal characters are understood in terms of their relationships with others</li> <li>Dickens' <i>Barnaby Rudge</i> is unusual for making the mentally disabled character the eponymous hero who contributes his own perspective on the action of the story</li> <li>Sympathetic portrayal of idiots</li> <li>Lunatic is perceived as more dangerous, morally corrupt</li> </ul>	<ul style="list-style-type: none"> <li>The capacity of people with mental disabilities and their place in society is articulated exclusively at a political level, in consultation with medical experts</li> <li>Government Inspectors and Superintendents observe the behaviours and living conditions of people with mental disabilities and depict them in reports that result in occasional revision of resource allocation and institutional standards</li> <li>Patients and family members are not directly consulted about the nature of therapeutic treatment, or personal daily living needs</li> </ul>
<b>Family Roles</b>	<ul style="list-style-type: none"> <li>Primary care providers</li> <li>Saintly maternal caregivers/martyrs</li> <li>Social deviants or morally corrupt individuals may pass degeneracy down to their children</li> </ul>	<ul style="list-style-type: none"> <li>Primary responsibility for care at the beginning of this phase</li> <li>Over time, and with the emergence of the "menace of the feeble-minded" (Simmons 1982, 65-109) professional care and control of idiocy and lunacy is endorsed</li> </ul>
<b>Community Roles</b>	<ul style="list-style-type: none"> <li>Coordinate charitable relief in cases of extreme deprivation</li> <li>Authority to step in where the (typically female) guardian cannot cope</li> <li>Generally indifferent/ambivalent</li> </ul>	<ul style="list-style-type: none"> <li>Taxes dedicated to finance poor houses, and then Provincial Lunatic Asylums</li> <li>Province steps in when communities not inclined/able to meet their obligations (minimal/residual support)</li> </ul>
<b>Institutional Option</b>	<ul style="list-style-type: none"> <li>Never depicted as a positive option</li> </ul>	<ul style="list-style-type: none"> <li>Initially intended as a last resort when families could not fulfill their responsibility</li> <li>Over time, promoted as in the best interest of the individual, family and community</li> </ul>
<b>REFORM PHASE</b>		
<b>How Their Stories are Told</b>	<ul style="list-style-type: none"> <li>Prevalence of life stories being told by other characters who know them</li> <li>Narrator's story and the disabled character's story are intertwined</li> </ul>	<ul style="list-style-type: none"> <li>More external expertise consulted in order to inform a policy of institutional reform</li> <li>Family perspectives are acknowledged as contributing to a shift in policy emphasis</li> <li>Advantages of community living are portrayed explicitly in terms of enhanced quality of life for people with mental disabilities; implicitly also advances a policy objective relinquishing</li> </ul>

		responsibility for a costly system of direct care
<b>Family Roles</b>	<ul style="list-style-type: none"> <li>Family connections nonexistent or dysfunctional</li> <li>More ambivalent portrayal of mothers and maternal figures: absence of a nurturing mother figure contributes to the vulnerability of the mentally disabled individual</li> </ul>	<ul style="list-style-type: none"> <li>Medical model emphasizes the expertise of professionals and institutional care as most appropriate; family relations undermined, as a result</li> <li>Growing grassroots “community living” movement is lead by parent activists</li> </ul>
<b>Community Roles</b>	<ul style="list-style-type: none"> <li>Nonexistent, or complicit with political agenda</li> <li>Social conformity/intolerance of difference a contributing factor to mental disability/madness</li> </ul>	<ul style="list-style-type: none"> <li>Increasing emphasis on community’s role/responsibility in supporting people with disabilities</li> </ul>
<b>Institutional Option</b>	<ul style="list-style-type: none"> <li>Rarely depicted as a positive option, but sometimes a necessary asylum in a cruel and intolerant world, or from family dysfunction</li> <li>Fosters dependence</li> </ul>	<ul style="list-style-type: none"> <li>Mixed messages: need for reform of the institutional system acknowledged and increasing emphasis on community integration even while institutional capacity continues to expand until mid 1970s</li> <li>Targets established for transfer to community living spaces, downsizing begins</li> </ul>
<b>DISMANTLEMENT PHASE</b>		
<b>How Their Stories are Told</b>	<ul style="list-style-type: none"> <li>Stories set in all phases on the Institutional Cycle, depicting the cultural/societal values of the time from the author’s contemporary perspective</li> <li>More first-person voices, complex characters who change over time</li> <li>In their relationships with the mentally disabled individual, the personal limitations of all characters are exposed</li> </ul>	<ul style="list-style-type: none"> <li>Pains are taken to demonstrate direct consultation with people with mental disabilities and their caregivers to enhance legitimacy of policy objectives</li> <li>A policy of ‘normalization’ of people with mental disabilities begins to cede to an environmental theory of disability that acknowledges and aspires to address ways that community structures disable others</li> </ul>
<b>Family Roles</b>	<ul style="list-style-type: none"> <li>Essential to the stories of disabled characters</li> <li>Personal struggles to meet the needs of their children</li> <li>Well intended, but human and fallible</li> </ul>	<ul style="list-style-type: none"> <li>Recognized as an/the expert in determining the disabled person’s best interests</li> <li>Care-giver role acknowledged but limits to supports inadequately supported/compensated</li> </ul>
<b>Community Roles</b>	<ul style="list-style-type: none"> <li>Ambivalent: sometimes well-intended, sometimes indifferent</li> <li>Community can exploit and be dangerous for people with mental disabilities</li> </ul>	<ul style="list-style-type: none"> <li>Emphasis on the community role/responsibility in supporting people with disabilities</li> <li>Advocating community living, but with limited resources</li> <li>Encourage family trusts &amp; DSPs</li> </ul>
<b>Institutional Option</b>	<ul style="list-style-type: none"> <li>Never depicted as a positive option</li> </ul>	<ul style="list-style-type: none"> <li>No longer a viable option</li> </ul>



representations of mental disability are in conflict. In addition, changes in the narrative construction of disability between phases of the Cycle tend to reflect changing political priorities. In some cases, political initiative influences a corresponding shift in cultural values. At other times, changes in social attitudes compel political change. The following discussion identifies dominant planning and disability theories, along with recurring narrative themes that, taken together, define the Establishment, Reform and Dismantlement phases of the Institutional Cycle.

### **Establishment Phase**

At the beginning of the Establishment phase the novels generally depict a greater degree of acceptance of the mentally disabled individual in society than is implied in policy from the same time period. Especially in rural locations there seems to be a place for ‘naturals’ and ‘idiots’, as long as their presence does not jeopardize the prevailing social order. Therefore, it makes sense that Dickens and Gaskell set their stories back in time, in small villages where families are long established, community ties are strong, and not yet affected by creeping industrialism.

Rapidly changing systems of production affected the social fabric of Canadian communities in similar ways as in England. Rice and Prince explain that after Confederation, as people left the farm for work opportunities in the growing towns and cities, they found that their lifestyles changed. There was less allegiance to, and reliance on, primary groups. The separation from the family and the farm created new situations, which required new ways of meeting one’s needs. Gone or declining were the rural communities with their single, unambiguous social structures. Gone was the sense of community that had seemed to naturally

protect the individual or family. Going or gone was the reliance on a self-sufficient environment. (37)

Structural economic change called for corresponding radical social change, and the establishment of the institutional system to replace the function that extended families and communities provided is indicative of this transition. The idiots and naturals that once had evoked a paternalistic response, at least in literature, came to be perceived as a burden on society where the individual's status became increasingly dependent on his or her capacity to participate in the waged labour market.

Barnaby Rudge and Willie Dixon are known in their communities and enjoy a degree of acceptance and support that many have struggled to attain since the institution was established as the dominant response to mental disability. Not surprisingly, the more directly involved that the mentally disabled character is in the life of the community, the more he or she engages with other characters who contribute additional dimension to their life story. Dickens' Barnaby Rudge is the most complex character considered in the Establishment literary sample because he is an active member of his community and can communicate a self-narrative that is proud rather than pathetic.

This ability to contribute a self-narrative is an important distinction that sets Dickens' idiot apart from Brontë's Bertha Rochester and Gaskell's Willie Dixon who are comparatively under-developed characters. The inability to speak for themselves leaves Bertha Rochester and Willie Dixon isolated and vulnerable to having their personal stories misrepresented by others who have a vested interest in their own versions of the lunatic's or the idiot's life story.

The isolation experienced by Bertha Rochester in *Jane Eyre* leaves her particularly vulnerable and unable to produce a life narrative to counter the one given by

her husband and jailor. Because no one even knows of her existence, there is no one to advocate on her behalf. The only character in a position to challenge Rochester's version of his wife's life-story is her brother Mason who tries to maintain an interest in his sister's well-being. However, by drawing his character as weak and susceptible to the same genetic taint that is perceived as responsible for Bertha's madness, Mason's advocacy for his sister has very little influence. Bertha Rochester's extreme marginalization speaks to the isolation of many people with mental disabilities who are dependent and vulnerable to abuse and exploitation at the hands of caregivers as well as strangers.

Each of the disabled characters from the Establishment novels epitomizes the moral model for constructing disability. The mental deficiencies of Barnaby Rudge and Bertha Rochester are both attributed to the sins of their parents. Even though Willie Dixon is not marked by the sins of morally degenerate bloodlines, he still is closely linked to a pastoral tradition that constructs the idiot as a child of nature and an eternal innocent who has the right to make claims upon the goodwill of the community.

Brontë's Bertha Rochester is portrayed as more depraved and morally reprehensible than either Dickens' Barnaby Rudge, or Gaskell's Willie Dixon. Even though the lunatic tends to be portrayed less sympathetically than the idiot, they tended to receive better institutional care. The institutional plan in Ontario was designed to separate the lunatics from the idiots, as the former were perceived to have some potential for cure and reintegration into society. Dr. Charles Duncombe chaired a committee whose report resulted in the 1839 Act to establish Upper Canada's first lunatic asylum. Historical analysis finds that

if the Upper Canadian policy-makers thought at all about mental retardation, they probably shared the conventional view that idiots were basically incurable. Since

contemporary lunacy policy was directed toward curing the insane, it is easy to understand why idiots were excluded from their [the Duncombe committee's] report and from the policy that emerged from it. (Simmons 3)

It was not until the late 1870s that incessant pressure to expand the asylum system, together with the growing perception that people with mental disabilities were responsible for the major social problems of the time, that the asylum model began to be replaced with a custodial system of care. From this point, “[m]entally ill and retarded people were no longer going to be protected from society, rather, society was to be protected from them” (Simmons 22). Although this analysis confines itself to the beginning of the Establishment phase of the Cycle, by the turn of the twentieth century a growing eugenics movement further accelerated the expansion of the institutional system in Ontario, as well as in England, Europe and the United States. The medicalization of disability eventually came to supplant the authority of parents and other informal caregivers, as mental disability increasingly became defined as a social scourge that needed to be professionally managed within the institution.<sup>62</sup>

This approach to planning most closely resembles Barclay Hudson’s synoptic theoretical framework to the extent that it was expert-driven, and designed with the stability of the overall social system as paramount, rather than the individual needs of mentally disabled people (389). However, at least in hindsight, any reference to a rational framework for disability policy planning at this point in the Cycle is severely undermined

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<sup>62</sup>In his historical overview of Ontario’s institutional system, Williston found that the “attitude of staff from central office right through to ward staff was, ‘We can take care of the retarded better than their families—that’s why they were sent to us... families should release their children to us and not interfere with our management.’” (29). This medical model of disability contributed to further estranging families from participating in the lives of institutionalized women and men.

by the flawed science and subjectivity that experts relied upon in the diagnosis and treatment of idiocy and lunacy at that time. Despite the absence of consistent, objective criteria for diagnosing idiocy and lunacy this theoretical foundation dominated policy planning and the development of the institutional system in Ontario until the Reform phase of the Institutional Cycle.

### **Reform Phase**

As a de-institutionalization movement gained momentum in the 1960s families were turned to again as key sources of support. Indeed, it is widely acknowledged that familial advocacy was key to inspiring political determination to reform the institutional system. This advocacy also provided the Ontario government with moral ground to justify a political objective of reducing and eventually relinquishing direct responsibility for the care of people with mental disabilities. Therefore, to the extent that Advocacy planning, as defined by Hudson's SITAR model (ch. 4) evolved at this time, it cannot automatically be assumed that social welfare planners were advocating exclusively in the interests of people with mental disabilities.

The renewed focus on family and the community as the preferred locations for the provision of care also fails to consider how an entrenched medical model for responding to mental disability had informed a longstanding policy of segregation and professionalization of daily living supports, which had estranged many individuals from their families. A substantial number of people leaving the institution had no intact family systems to which to return. In addition, by the end of this phase of the Cycle the decision in *Clark v. Clark* (1982) challenged the presumption that family members are necessarily the best interpreters of another's life and its potential. The fact that when Reform-era

novels do depict family systems they are often portrayed as dysfunctional or unequal to the task of supporting the mentally disabled character further reinforces this finding.

By the time policy-makers became motivated to reform the institutional system, novels that criticized the institution also often emphasized the need for asylum from a society that is unaccommodating and even intolerant of diversity and mental difference. The Reform-era novel is increasingly considering disability as a category of identity that intersects with social class, ethnicity, gender and sexuality. Rhys, for example, shows Antoinette Cosway as prey to such problems. Antoinette embraces the convent to escape from the persecution that she experiences in her community, and she is subsequently reluctant to leave this asylum to assume her prescribed role in society as a matrimonial bargaining chip. A social justice theory of disability influences the storyline of *Wide Sargasso Sea*, as the novel demonstrates how policy founded on patriarchal and colonizing traditions contribute to the mental deterioration of Mrs. Rochester and even creates the ‘madwoman in the attic’.

In Kesey’s *One Flew Over the Cuckoo’s Nest*, McMurphy is astonished to learn that most of his fellow patients are voluntary inmates who prefer the routine persecution that they experience on the psychiatric ward to the marginalization and violence they encounter in the outside world. The novel implicitly critiques a medical model of disability and, instead, gives credence to an environmental approach that suggests that societal attitudes contribute to disabling people by resisting the inclusion of people who do not conform to social norms. Several of the patients in the ward are casualties of structural discrimination in society that is shown to break down people who are not white and not heterosexual. The “therapeutic community” is in place to realize the functional

theoretical objective of teaching people with mental disabilities to emulate the norms of mainstream society so that they may succeed outside of the asylum.

Even at the end of the Reform phase, when the community living movement is well underway, some popular fiction continues to presume that people who cannot be taught how to live independently in society are better off in the institution. Krantz's *Princess Daisy* was a best-selling novel in the early 1980s, but the narrative does not even consider that a mentally disabled young woman could live more successfully in society than in a segregated asylum. Money determines Danielle Valensky's security and the quality of life she is able to enjoy in a private institutional facility. Most of the novel's storyline revolves around the heroine's efforts to support and maintain her sister in the institution. Daisy Valensky's efforts are portrayed as an act of loving selflessness to protect her secret twin from a world that is depicted as obsessed with beauty and glamour.

The social critique contained in the Reform novels offers a striking contrast to the optimism of Reform policy regarding the capacity of communities to accommodate and care for people who would otherwise spend their lives in an institution. This is apparent in Ontario's Provincial Secretary for Social Development's response to Williston's report where Robert Welch asserts that "[a]s a necessary precondition to a life of normalcy, in both institutional and community settings, mentally *retarded persons must be encouraged and allowed to make their own decisions and determine their own needs, as far as this is possible*" (9 emphasis in original). Welch believed that society was prepared, in 1973, to accommodate the needs and life choices of people who would otherwise live in institutional facilities.

Williston was more cautious. In fact, he never called for the complete dismantlement of the institutional system. Instead he recommended that the large

institutions be “phased down as quickly as is feasible” (65). His primary reason for not urging outright abolishment was concern about community capacity to accommodate people with the most profound intellectual disabilities, as well as the viability of community re-integration for those who had already spent many years in an institutional environment. Other reasons for maintaining at least a small scale institutional presence as part of a continuum of services and supports for people with mental disabilities emerges from an acknowledgment that “[i]t is too much to expect that a family can indefinitely look after a person who can never learn routine habits of daily living” (Williston 69). While the significant financial savings that would result in closing the institutions enhanced the appeal of a community living movement at a political level, this was not part of Williston’s rationale for endorsing a scaled back institutional system. He further adds that the “furnishing of the basic necessities and support to enable a person to function in society must be recognized as a basic human right to be provided at public expense and not discharged as a matter of chance or charity” (4). He recognized that putting the necessary community supports in place would take time, and that it would also take time to educate members of society about the citizenship rights of people with mental disabilities. For these reasons, Reform policy was implemented incrementally to maintain stability in the system. Enhancing community capacity was planned in coordination with the gradual erosion of resources dedicated to the institutional system in a series of trade-offs and stakeholder negotiations communicated through a rhetoric of human rights and community integration.

Despite the gradual progression of reform, however, this stage of the Institutional Cycle is defined by striking conflict between the rhetoric of Reform policy and the dominant representations of disability and society in novels. This contributed to a degree



of social confusion and ambivalence about how to include people with mental disabilities in mainstream society, which is apparent in the novels and policy discourse in the final phase of the Cycle.

### **Dismantlement Phase**

The conflicting representations of community in Reform novels and policy anticipate the uncertain successes of the Dismantlement phase: the political objective of closing down Ontario's institutions is accomplished, but there are many people living in poverty and without access to a comprehensive range of daily living supports that are necessary in order to participate in their communities in meaningful ways. An incremental approach to planning persists, despite policy rhetoric that in recent years has promised a "transformation" (Government of Ontario 2006; Parsons 2006) of services for people with developmental disabilities. The transformation being proposed entails a shift to more individualized planning and designated resource allocation. However, to date, the overall trend has been in the direction of diminished political commitment that is apparent in terms of the erosion of systemic supports, and diminished enforcement of high standards of care for vulnerable citizens. Even the Government of Ontario has acknowledged that the necessary spectrum of services and supports are not equally accessible in all regions of the Province (2006, 34).<sup>63</sup>

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<sup>63</sup>For example, the North Eastern Mental Health Centre (NEMHC) recently expressed its support of the Northeast Ontario Local Health Integration Network's (NE-LHIN) decision to relocate 31 long-term psychiatric beds from North Bay to Sudbury. The region contained within the boundaries of the NE-LHIN is several hundred kilometres, containing many communities. In its release, the NEMHC submission includes the following recommendation: "The North East LHIN should make the quality and effectiveness of programs and services the first priority. Although the delivery of services as close to home as possible is an important factor for some patients, it should not be the first priority." (NEMHC para. 11-12)

Community integration is dependent upon the provision of resources necessary to allow persons with mental disabilities to participate in the life of the community.

Marginalization is compounded when people continue to experience segregation in mainstream society. Dismantlement novels depict how issues of segregation that were once considered in relation to residential facilities are now debated in schools or day programs where the rhetoric of inclusion sometimes co-exists with enduring habits of paternalism and discrimination. For example, in Haddon's novel Christopher Boone's father has to advocate for the opportunity for his son to take university qualification exams because the principal does not want to treat him differently from the other students in a school dedicated to 'special needs' students. This speaks to a problem in policy that distinguishes people with disabilities from the mainstream population, but fails to recognize the diversity of ability and need within a demographic that comprises 4.4 million Canadians who have some form of disability (Prince 2009).<sup>64</sup>

Dismantlement novels set in previous phases of the Cycle speak to contemporary community living issues that still resonate in a post-institutional era. In the sample considered for this research, Findley portrays the asylum system in Ontario in 1918, and Edwards depicts an American institution in 1964.<sup>65</sup> Yet these novels, together with Haddon's contemporary story about an autistic boy living in a suburb of London, are speaking to contemporary challenges in communities that continue to struggle to facilitate the inclusion of all people. In Findley's *The Piano Man's Daughter* Lily Kilworth and

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<sup>64</sup> As reported by Statistics Canada, based upon most recent (2006) data. Ontario's Ministry of Community and Social Services indicates that "about one per cent of Ontarians have a developmental disability" (3 August 2010), and that 30-38 per cent of people with mental disabilities also have a "mental health disorder" (MOHLTC & MCSSS, 3).

<sup>65</sup> In addition to Findley's and Edwards' novels, other fictional narratives set in Reform or Establishment phases of the Cycle include: Hegi, *Stones from the River* (1994); Rubio, *Icy Sparks* (1998); Bender, *Like Normal People* (2000); Clark, J., *An Audience of Chairs* (2005).

her son are insecurely housed. They move from rooming houses and hotels because one of the symptoms of Lily's disability is the recurring compulsion to "escape" from the internal voices that persecute her. The only thing that keeps her from being homeless or institutionalized is the financial and personal support that her mother is able to provide. When Lily can no longer live safely in the community, and the family's financial resources have declined, the institution becomes Lily's only residential alternative. This is a storyline that is familiar to many individuals with mental disabilities who are languishing in prisons, hospitals and long-term care facilities in Ontario today.

The personal challenges associated with moving from family to other supported living arrangements is portrayed in Edwards' *The Memory Keeper's Daughter*. Caroline Gill's anxiety for her daughter, Phoebe, as she transitions into adulthood depicts the fears that many parents have for their mentally disabled adult children once they want to live on their own, or when the time comes that parents are no longer able to provide daily living care. Currently, when this happens often the only option available is long-term care facilities for the sick and elderly. In 2007 the *Toronto Star* reported that the institutional dismantlement process had resulted in 1600 developmentally disabled adults being "moved into Ontario nursing homes with people often twice their age" (Crawford 16 Feb. 07, para. 1).<sup>66</sup> Such findings suggest that the elimination of one institutional system has only put additional pressure on others, and as communities continue to struggle to care for people who require intensive personal supports, the influence of the institution lingers.

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<sup>66</sup> The appropriateness of attempting to integrate younger adults into long-term care facilities designed for elderly people with dementia and other acquired disabilities was brought under even closer scrutiny following the death of Keith Croteau who was killed by his roommate following an altercation over the television remote control in February 2007, in Sudbury. Laura Stradiotto (Feb. 6&7, 2007) reports that the assailant and Croteau both had developmental disabilities and were residing in a facility not equipped to address with their specific living and personal security needs.

The Institutional history in Ontario has been conceived here as a Cycle that begins with the Establishment of the first Provincial Lunatic Asylum in Upper Canada, in 1839, and concludes with the closure of the province's final institutions in 2009. However, it is perhaps more accurately conceived as a spiral. Representations of mental disability in policy and literature are more informed and complex than they were at the outset of the Cycle. Certainly, many positive changes have evolved over the course of the Institutional Cycle in terms of society's understanding of the human rights of all citizens, including people with mental disabilities. Canada has some of the most comprehensive human rights legislation in the world that specifically identifies people with disabilities as a population whose citizenship claims must be assured. Rioux and Frazee conclude that

[t]here is, perhaps, some cause for optimism as the Canadian human rights and disability rights perspectives continue to mature and as litigation strategies build upon our Supreme Court's growing recognition of the nature and extent of disadvantage experienced by disabled persons, and of the imperatives of inclusion, autonomy and human dignity.

The goals of justice, equality and diversity are inextricably linked and strongly resonant in the recurring themes of Canadian disability law. (185-186)

A social justice theory of disability argues that people are disabled by policy that discriminates against marginalized groups. However, rights in theory are meaningless if they are not enforced, and if the resources required to realize citizenship rights are not accessible (Goar, 29 May 09). This discourse analysis of texts that represent the rights and the stories of people with mental disabilities finds that the realization of citizenship claims has not been a linear process; and that gains, once achieved, are not assured over the long term.

**Chapter 10- Limitations**

There are several limitations to this research project that suggest opportunities for further inquiry. These limitations pertain to: conceptual limitations of the Institutional Cycle framework; limited analysis of other theoretical models that have influenced the representation of people with mental disabilities, particularly a medical model of disability theory, which has been dominant over most of the course of the Cycle; and limited representation of the diverse population who have disabilities that limit or preclude the ability to speak for themselves.

The decision to confine the analysis, in the Establishment phase, to novels and policy produced close to the inception of Upper Canada's first lunatic asylum, in 1839, excludes a number of significant texts for consideration. While the timeline for the Establishment phase reflects the course of the institutional system's long period of expansion, the reasons for this expansion changed over time. Ontario's first provincial lunatic asylum was established as a residual welfare policy of last resort. However, over time an increasingly dominant medical model of understanding disability invigorated the expansion of this system. By the turn of the century, an evolving eugenics movement contributed to a notion of a scourge, or

fear that mentally retarded persons would soon overpopulate the land. It was repeatedly stated that the great majority of the feeble-minded came from family stock that transmitted feeble-mindedness from generation to generation. Some even contended that feeble-mindedness was an important factor as a cause of juvenile delinquency, adult crime, sexual immorality, prostitution, the spread of

venereal disease, illegitimacy, vagrancy, and almost every other form of social evil or disease. It was widely believed that every intellectually impaired person was likely a delinquent and that most criminal offenders had an intellectual impairment. (Williston 23-24)

Further research into dominant literary and policy discourses from 1900-1960 could introduce an additional phase of “Expansion” or “Entrenchment” into the existing Cycle.

The policy and literary discourses that comprise the sample do not address the positive ways that a medical model of disability has contributed to enhanced life opportunities for some people with severe mental disabilities. Indeed, it is noteworthy that, apart from Kesey’s *One Flew Over the Cuckoo’s Nest*, this dimension of mental disability is largely ignored in the sample. The role of medication and other therapeutic interventions has been a contentious issue for many disability scholars and advocates who perceive the medical model of disability as primarily a negative framework for understanding disability in terms of its focus on individual impairment and deficiency. However others, such as Oliver Sacks and Margaret Somerville, speak to ways that medical science may make a wider spectrum of living options feasible for some people when this knowledge is used to advance individual choice in a society that values all human beings.

Regarding the validity of the data sample, it is important to acknowledge that novels can only be one more secondary source to access in bridging the gulf between the individual’s self-narrative and the one that is reconstructed from a range of other sources, including the expertise of policy planners, medical professionals, and family members. Appealing to novels, or literature generally, does not solve the problem of speaking for others. However, novels are useful to policy planners and other social workers for

bringing “potentially universalizable concrete prescriptions” (Nussbaum 8) to bear on specific situations. This research shows that literary fictions dealing with mental disability can be a valuable resource for informing planning with for people with mental disabilities by depicting how abstract policy objectives impact personal life narratives, and by representing a wider spectrum of ability and oppression experienced by people with mental disabilities than is typically perceived by the reading public.

Even when people with mental disabilities are able to communicate their life-stories in a coherent and reliable fashion, this is not a homogenous population who share identical experiences and aspirations. In addition, while this research has aspired to examine stories about people who have mental disabilities that compromise their ability to speak for themselves, it needs to be noted that in most of the novels considered for analysis the characters have communicative abilities that far exceed those of many people with severe disabilities. Almost all of the characters have some facility in language, or at least caregivers who know them intimately and try hard to advocate for their best interests. In reality, many people with complex mental disabilities have few personal resources. Ongoing analysis of diverse perspectives contained in fiction and nonfiction narratives, together with archival research of legislation, commissioned reports, program reviews, media reports, journalism, and personal papers that fall outside the parameters of this current research will continue to enrich the integrity of these initial findings.

## **Chapter 11- Recommendations**

### **How May an Interdisciplinary Analysis of Literary and Policy Discourses Inform Policy Planning and the Provision of Services for People with Mental Disabilities in Ontario?**

At the beginning of a post-institutional era the findings of this interdisciplinary research reflect upon the dominant planning assumptions and storylines that have defined the phases of the Institutional Cycle. This research has looked to the past to better understand the life stories of people with mental disabilities today, and the following conclusions identify policy priorities for the future that draw from the learning that the Institutional Cycle has to offer. The following recommendations address those locations of intervention that have been found to most directly influence the life stories of people with mental disabilities: family, community, and policy systems.

#### **Family Supports**

In the novels considered in this research, across all phases of the Institutional Cycle, all of the characters who succeed in society have substantial family supports to draw upon. To varying degrees, the novels also depict the personal toll that caregiving takes on family members, especially in the absence of structural supports. It has taken a long time for policy makers to acknowledge Williston's observation that "[t]he presence of a mentally retarded person can cause great strain on the family as a whole. The families which care for the mentally retarded are heavily penalized both materially and in their social life... Social isolation and rejection may ensue as a result of the reduction in



social contact” (71). Contemporary novels critique Dismantlement policy in storylines that depict how the responsibility of care for children with complex disabilities competes with the other roles, duties and dreams of caregivers. The caregivers, in turn, may become so exhausted and isolated that they become estranged from the very communities that they are trying to access for their children. Resources need to be made available to significantly enhance the amount and the range of supports available for families trying to support relatives with mental disabilities.

There is overwhelming evidence that families require more comprehensive supports to fulfill the caregiving roles that current social policy assumptions depend upon. As the Dismantlement phase has progressed the Ministry of Community and Social Services has increasingly emphasized policy that promotes system sustainability through personalized planning to facilitate “better management of funding pressures” (Government of Ontario, 2006, 12). However, Pedlar and Hutchison point out that one of the risks associated with personalized planning is the commodification of care that promotes

[p]rivatization, contracting, negotiating... [These] are signs of restructuring of human services that are driven by a competitive, business ethic, rather than a human rights and community ethic. In this climate, disability becomes a commodity, as agencies determine the value of servicing the individual and establish whether or not sufficient dollars will accrue in committing to serve the person. (645)

If the government of Ontario is going pursue an agenda of individualized planning for people with mental disabilities, then supports should realistically meet the needs of the individual.

Currently, the bureaucratic labyrinth that families must navigate to obtain resources is discouraging, and often only adds to the demands associated with caregiving. Ian Brown explains that, in Ontario,

[t]here are some tax deductions available, but both Johanna and I work, so our income is generally too high for us to be eligible, we discover after we fill out the schedules. There are programs to cover the costs of assistive devices, but they require mountains of paperwork, not to mention background checks: the government seems to think I might have reason to scam a netted bed and an IV stand. Just what I always wanted! In any event one of us ought to fill out these forms—but both of us are working and looking after Walker full-time. When we both begin to freelance, to give ourselves more flexible hours, the forms do get filled out—Johanna spends four hours a week on paperwork—but we make less money, whereupon we can apply for those tax deductions. (86)

Another integral part of a personalized planning approach encourages parents to make long-term investments for the care of disabled children through trusts and disability savings plans (DSP) to finance ongoing daily living support throughout the lives of their adult children (Government of Ontario, 2006, 27). Yet again, the onus is being placed on families to assume lifelong responsibility for children or siblings who will never be able to care for themselves. Tax breaks may be helpful for some, but given how much of the general population cannot afford to contribute to a retirement savings plan (RSP), a DSP is not going to be a viable long-term security option for many.

In addition, respite services should be made accessible and affordable for family caregivers on a regular basis. Currently, home-care agencies offer predominantly low-paid, contract employment, and turnover is common (Brown 85-86). Access to qualified

developmental service workers, who are employed full-time through local Community Care Access Centres might reduce demand for the scarce residential spaces available for people with complex needs. Furthermore, paying these professionals a wage that reflects the responsibility attached to their work<sup>67</sup> is still a cheaper alternative to supporting people in long-term care facilities and group homes that continue to segregate people with mental disabilities on the margins of communities. Introducing respite care as a stable and consistent feature of community living would allow individuals with severe mental disabilities and their families to build rapport with qualified caregivers and approach a better balance between caregiving and other roles and responsibilities that people pursue to realize personal fulfillment.

In recent years, the provincial government has taken pains to demonstrate how their planning for people with mental disabilities has been informed by consultation with families. Unfortunately, over the course of stakeholder consultations in the Dismantlement phase, Parsons found that there “appears to be a perception by some parents that the government possesses unlimited funding for supports. Indeed, a significant number expressed the belief that ‘we have cared for our children for years, saving the government millions, and now it’s the government’s turn to pay us back’” (13). In fact many familial caregivers feel that they have been poorly supported in terms of meeting the financial and personal costs of caring for relatives with complex disabilities.

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<sup>67</sup> A Toronto agency advertised the following job description for a personal support worker (PSW), the lowest professional qualification for caregiving work: “Provide personal care services and ensure that clients are emotionally, spiritually and physically comfort [sic.] and safety of clients are met to the greatest possible extent; provide personal care including skin care, hair care, bathing, bowel and bladder care, positioning and movement, exercise, basic wound care, feeding including special diets, and assistance with medication administration and oxygen; perform specialized, client specific procedures for which recognized training and current competency can be demonstrated; observe and document client conditions according to company standards; monitor and report unusual changes in client condition...; understand and implement infection prevention practices.” (working.com, 9 July 2008).

As Hudson defines a transactive approach to planning, the process must entail a commitment to mutual learning, and a willingness to work for the objectives that constituents identify (389). Too often, however, consultation amounts to recording an inventory of unmet needs that government concedes are important, but not economically feasible. When families are too overwhelmed by their responsibilities to advocate for people who cannot advocate for themselves, social workers have a role to play in working to make these individuals and families visible in their communities and to make their stories known.

Currently many families are trying to coordinate fragmented community services and committing themselves to constantly being on-call. Crisis management becomes a way of life. In a *Globe and Mail* feature, published in the same year that Ontario closed its last institutions, John Allemang reports on the life and death of Alexandra Smith: a woman diagnosed with severe learning and mental disabilities, who never successfully found her place in the community. Allemang learned the story of Alexandra's life through interviews with her immediate family, who were also her care network and found that

[w]e've let the mentally ill out of their institutions, because it's seen as the humane thing to do, or because it saves money, or because it scores a political point. But a family's perspective when one among them is mentally ill is different: Their compassion for these lost souls—or failing that, their responsibility to foresee the worst—is obligatory, whether they like it or not. (2009, F1)

Policy-makers continue to insist that they recognize how “[c]aring for an individual with a developmental disability can be exhausting, placing unreasonable strain on relationships within families” (Parsons 9), and that “families often need help” (Government of Ontario,

2006, 17). Still, for many families the help that is available is woefully inadequate to their needs.

### **The Community Institution**

There are at least two major assumptions associated with the concept of de-institutionalization that need to be interrogated. First, it is important to determine if people are living better lives in the community than they did in institutional facilities. The second assumption that social workers and other advocates need to reflect upon is the belief that all people want to integrate into mainstream society.

Most people with severe mental disabilities cannot afford the costs of comprehensive daily living supports, and those people who do not have access to trust funds, Disability Savings Accounts or other personal insurance provisions are almost certain to be poor. Poverty marginalizes people from mainstream society, and it compromises both health and self-esteem. When the benefits of community integration are discussed, the ways that poverty contributes to social exclusion and compounds disability are not adequately considered. Without money, a person's sphere of activity is inevitably small. Twenty-two years after the publication of the Challenges and Opportunities planning vision, John Allemang published the life story of a young woman whom her mother described as ““terribly angry... She just hates the way she is. We have this idea that people like this can live in the community, but what is her community? She doesn't leave her room except to get coffee and cigarettes”” (Allemang F6). Alexandra's life-story, as given by those who knew her, demonstrates that physical relocation from institution to an apartment does not satisfy the objectives of community living.

It is hard to visit some behavioural group home residences and not wonder how the structure and the regimen of these “homes” differ from typical descriptions of institutional life, except perhaps in scale. Indeed, contemporary research finds that

[r]elocation to community-based services is not sufficient to overcome isolation: services and residents also need contact and interaction with outsiders.... Where individuals have little contact with family, friends or advocates, are in out-of-area placements or receive all their support within a single service, they are isolated from the support and vigilance of others and standards of care receive little monitoring, increasing the risk of abuse and of abuse remaining undetected.

(White, Holland, Marsland & Oakes, 7)

When planning documents describe “[p]ermanent accommodation for adults with persistent high-risk behaviour who require ongoing specialized support... a safe, secure, therapeutic, long-term home” (Government of Ontario, 2006, 26), how is this different from the institutional facilities that have just been officially decommissioned?

The Developmental Services Act was the legislation that governed the operation of nonprofit supported living facilities until it was replaced in 2008 by the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act.<sup>68</sup> Part V of the Developmental Services Act delineated “Rules Governing Facilities”. These rules set minimum standards for maintenance, staff training, and regular inspections in order to ensure that “adequate supervision is provided at all times for the security of the residents and the facility” (V.11n).

Today, “[m]inistry-funded homes for adults with a developmental disability are not licensed by the province... each provider of residential services must complete a

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<sup>68</sup> This legislation is being phased in and has not yet been fully implemented.

checklist of requirements focused on the personal health and safety of people living in ministry-funded homes” (Government of Ontario, 2006, 29). However, the question of enforcement of standards is not clearly addressed in the most recent legislation. The new legislation is less specific in defining criteria for standards of care in supported living facilities. Part VI of the new Act addresses “Rules Governing Services Agencies”, but these do not legislate a specific set of resident rights, or a regular reporting protocol, only that a “service agency shall, (a) make a report to the Minister whenever the Minister requests it, in the form and containing the information specified by the Minister, and (b) comply with such other requirements as may be prescribed” (VI-25). To date such protocols have yet to be prescribed. The Ministry of Community and Social Services did acknowledge in its consultations about the new legislation that the developmental services sector has not had to operate under the same rigorous standards as residential facilities for children and seniors.<sup>69</sup> Parsons pledges that as the government “moves forward with the transformation of the developmental service sector consideration must be given to developing a regulatory and legislative framework to ensure that clients are getting the services they require to improve their quality of life in the community. There is currently a lack of regulation regarding these operations” (Parsons 12). The implications of this “lack of regulation” are worth dwelling upon.

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<sup>69</sup> Trish Crawford (3 April 2009) reports that resident deaths that occurred in provincially-run facilities triggered a mandatory investigation, but this is not necessarily the case in community facilities where serious injury and even death are at least perceived as being more easily attributed to natural causes. Specifically, Crawford is reporting on the case of June Elliot who died in a residential group home following her transfer from the Huronia facility, where she had lived for thirty-five years. Crawford reports that “intellectually disabled adults in group homes do not have the same protection—such as regulated staffing, nutrition and hours of care—as the elderly in nursing homes or children in day care” (A4). The article further reports that in the first four months of 2009 there had been 53 deaths in group homes: most, according to MCSS, as a result of natural causes, although no breakdown is given, citing privacy concerns.

In his analysis of contemporary disability policy planning, Michael Prince points to how the community living movement continues to call for the closure of institutions in Canadian jurisdictions where they still exist (186) despite case evidence that indicates that many people are not only unhappy, they are unsafe in environments where they cannot count on access to round-the-clock care and life planning. However, stories of intimidation, exploitation and abuse are reported on sporadically, and often not at all.

Allemang's report on the life and death of Alexandra Smith is just one example from a file that is thick with news articles collected over the course of this research: People living in hospitals and nursing homes because an appropriate supported living space just doesn't exist for them (Crawford 16 Feb 2007; "A Hospital is Not a Home" 25 Aug 2008; "Time to Address Needs of Disabled..." 19 Feb 2009); people suffering and dying from neglect and other forms of maltreatment at the hands of family members not equipped to support their daily living needs (Mitchell, 13 Oct 2007, A11; Mitchell 20 June 2008; Russell AA7). Sometimes people die as a result of living in a long-term care facility for the elderly that does not have a mandate or the staffing to meet the needs of people with distinct mental health needs (Crawford 3 April 2009, A4; Stradiotto 6 Feb 2007, 7 Feb 2007). People have died in conflict with the police when crisis-intervention services have not been coordinated and enabled to intervene in time (Morrow 9 Oct 10). There are people stranded in hospital emergency rooms with nowhere else to go because their group home won't take them back ("System Fails Man Left in City's ER..." 1 Dec 2007); people languishing in jails because other secure, supported living options do not exist (Adams A11; Crawford 14 April 2008; "Death by 'Therapeutic Quiet'" A20; Picard L1, L4; Walton A8); and there are people living "independently" in the community who are easy prey for others to abuse and exploit (Friesen A1, A4; Morse 20 Feb 2009). The



stories of people with limited or no ability to directly influence their living conditions in should be very important to social workers and all citizens. The Institutional Cycle demonstrates that policy change tends to occur in response to an individual tragedy that raises community awareness, and subsequently reveals systemic crises. Vulnerable people living in private homes, small apartments and rooming houses, or in small nonprofit agencies trying to optimize the quality of life for residents with very complex needs on very tight budgets easily become invisible. How is the care of vulnerable people regulated in far flung communities with inconsistent access to specialized services and supports necessary to support the daily living needs of all?

Given the diversity of need and the demonstrated limitations of policy and community capacity, planners need to consider whether the ambitions and social norms of mainstream society are being imposed upon people who may aspire to something else. At the outset of the Dismantlement phase, the Opportunities and Action Initiative articulated a vision of “fairness and equity” for people with developmental disabilities that will “[c]reate opportunities in everyday life that are the same, or as close to as possible, to norms and patterns that are valued in the general mainstream society” (Government of Ontario, 2006, 15). Such an objective assumes that all people aspire to replicate the “norms and patterns that are valued in mainstream society”. It is the rhetoric of a policy of normalization and assimilation that is reminiscent of the Combine in Kesey’s, *One Flew Over the Cuckoo’s Nest*.

In the drive to make community integration possible for people with all kinds of mental disabilities planners may be labouring under the false assumption that everyone wants to be a part of the kind of society that is being made available to them. In *The Piano Man’s Daughter*, Findley portrays a heroine who disappears periodically to escape

a world that confuses and hurts her: “The first time Lily escaped, she was gone no more than a minute before it occurred to her that, going into hiding, she had found a way to rid the world of others—and to claim it for herself” (Findley 109). Near the end of Haddon’s *The Curious Incident of the Dog in the Night-time*, Christopher Boone describes a recurring dream about living in a world where most of the population has been killed off by a computer virus:

And eventually there is no one left in the world except people who don’t look at other people’s faces... and these people are all special people like me. And they like being on their own and I hardly ever see them because they are like okapi in the jungle in the Congo, which are a kind of antelope and very shy and rare. And I can go anywhere in the world and I know that no one is going to talk to me or touch me or ask me a question. (Haddon 198-199)

Christopher’s dream world is one where he is almost entirely alone and able to move wherever he wants to go, free from the stress that human contact poses for him.

Such passages give pause and invite one to reconsider whose needs are the policies of Dismantlement prioritizing. Ian Brown also has a dream of a society that he envisions for his son, Walker:

In my fantasy, Walker and people like him live in a L’Arche-like community, with the help of assistants. It’s a beautiful place, in a beautiful spot, with a view of the sea or the mountains, because for once, in this place, it isn’t just those who can afford them who have access to the best views, but people who might need beauty even more, because they live with so much less. In my fantasy, this village is owned and inhabited by the disabled, on their schedule, at their pace, according to their standards of what is successful—not money or results, but friendship, and

fellow feeling, and companionship. In my fantasy, it is the rest of us, the normals, who have to be “integrated” into their society, who have to adapt to *their* pace and their place. (Brown 270-271; emphasis in original)

Brown sees this fantasy-community as a place where people like him can go to live for weeks, or months at a time; bring their work or their research and just allow themselves to learn from people whose work is to just be in the world and remind the rest of us about the fundamentals of being human. Christopher Boone and Ian Brown talk about community in ways that take the emphasis off integrating people with mental disabilities into environments that just cannot accommodate them.

Allemang concludes his story about the life and death of Alexandra Smith by deciding that “for someone whose violent tendencies were enhanced by an inability to sense the subtle details of daily life, independence finally became a burden” (F6). It is unclear how many are struggling in circumstances similar to Alexandra’s where, in the words of her father, “[w]e say it’s good for her to be in the community. But the community damn well doesn’t want her” (Allemang F7). It is clear that the claims of the Challenges and Opportunities Initiative that ushered in the Dismantlement phase were premature. It was not true in 1987 that the “efforts of government, community agencies, developmentally handicapped people and their families have proven that all can work together towards realization of the dream of full participation of all developmentally handicapped citizens in Ontario” (Government of Ontario, 9). Instead, today many people are segregated in group homes and rooming houses without adequate resources

and other supports to actively participate in the community on a regular basis. Many others are unable to claim even that much space in society.<sup>70</sup>

Brown suggests that living in a segregated environment, at least part-time, offers a better environment for his son to develop his personal confidence than the wider community can provide. From his journal notes documenting his son's transition to residential care, Brown observes how "*it's his emotional confidence that's leaping forward. Living only in our world, I'm sure, he saw his limitations everywhere. In his new vacation home, as I think of it, surrounded by his peers, he's as solid as anyone. I hope that is the gift we gave him by giving him up*" (109). It is notable how Brown avoids using the typical language of residential care, preferring to think of his son's new place as a "vacation home." Given the notorious legacy of the institution, it not surprising that any model of long-term residential care is difficult for many people to contemplate as a positive care option for some people.

However, de-institutionalization outcomes should prompt planners to revisit the findings of the report that policy makers have continued to invoke to justify the elimination of the institutional option. Williston believed that limits should be placed on freedom in the interests of personal security. He recommended a spectrum of supported housing options ranging from group homes, to specialized foster care, half-way or transition housing, and long-term care facilities (75-80) that collectively provide a better range of community living options and personal supports to meet individual needs than are currently available in most communities. Getting beyond an either/or dichotomy of

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<sup>70</sup> Among the recommendations of the coroner's inquest examining the circumstances leading to the death of Byron Debassige who was shot in a confrontation with police, on Feb. 16, 2008, "were that the province [of Ontario] should assess the need for more supportive housing for those with mental illnesses and addictions, [and] fund more psychiatric care in the community..." (Morrow A24)

institution or no institution is the first step to transforming services for people with mental disabilities in a meaningful way. Recognizing that residential care does not need to resemble the institutional model that was abandoned for very good reasons is the next step. Realizing that the future does not need to look like the past takes planning further down a road of personalized supports that are flexible enough to offer community living and personal security.

### **Policy Coordination and Standards of Care**

The literary sample considered for this research rarely challenges specific policies directly. However, the nine primary literary sources, along with several other novels that reinforce dominant narrative themes, collectively depict the lack of coordination of services and inconsistency in programming and resources across jurisdictions. In March 2010 Canada ratified the United Nations Convention on the Rights of Persons with Disabilities, yet currently there are no national standards of care or inclusion for people with mental disabilities in Canada. In 1998 the federal and provincial governments (excluding Quebec) collaborated on the In Unison accord, which attempted to re-assert the citizen rights of people with disabilities in Canada that were already enshrined in the Charter of Rights and Freedoms and provincial human rights legislation. While some disability theorists point to the limitations of the Accord in terms of how it defines disability as a problem to be solved (Michalko 146-148; Titchkosky 49-63), others saw it as a foundation upon which to build a Federal Disability Act to set national standards for daily-living supports for Canadians with mental and physical disabilities.<sup>71</sup> However, this

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<sup>71</sup> See The Canadian Council of Disabilities. "A Federal Disabilities Act: Opportunities and Challenges". (2006) <http://www.ccdonline.ca/en/socialpolicy/fda/1006#background>

initiative ultimately has not translated into any meaningful coordination of policy between the federal government and provincial jurisdictions.

That being said, the existence of national standards has not meant more consistent and comprehensive services for people whose disability is defined in terms of mental illness either. The recent coroner's inquest into the death of Byron Debassige concluded that "Ontario must do a better job of sharing records on mentally ill people between agencies and create a single organization to coordinate all mental health and addiction services" (Morrow A24). The Canada Health Act defines criteria to which all provincial health insurance plans must adhere.<sup>72</sup> However, the Kirby Commission found that the coordination of mental health policy in this country is just as complicated and confused as the ad hoc system of services for people with mental disabilities, across provincial jurisdictions. The Commission's detailed report found that the mental health system in this country continues to be mired in "confusion, misdirection and discrimination" (Kirby xvii). This confusion is further compounded by the fact that the distinction between mental illness and disability, as well as eligibility for services, continue to be inconsistent across and within jurisdictions.

Given that social policy design and service delivery is primarily a provincial responsibility, perhaps working from the bottom up is the most effective approach to establishing a comprehensive and consistent national system of community living supports. Improving coordination of inter-ministerial mandates at the provincial level has been contemplated in the past, but to little affect. In 1971 Williston commented upon the

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<sup>72</sup> "In order that a province may qualify for a cash contribution referred to in section 5 for a fiscal year, the health care insurance plan of the province must, throughout the fiscal year, satisfy the criteria described in sections 8 to 12 respecting the following matters: (a) public administration; (b) comprehensiveness; (c) universality; (d) portability; and (e) accessibility." (Canada Health Act, Sec. 7)

inefficient coordination of planning between ministries responsible for promoting the care and social inclusion of people with mental disabilities:

The effectiveness of Government policy-making and its implementation as it affects handicapped persons is seriously impeded by the number of Departments and Branches which are independently trying to deal with one overall situation.

This division of responsibility has had a deleterious effect upon policy, the use of resources, public accessibility, accountability, and co-ordination. (90)

In his report, written two years later, Welch acknowledged that effective delivery of services for people with mental disabilities required the coordination of no fewer than six ministries (6). However, he also suggested that there are limits to the extent that streamlined planning for disability services and supports could be achieved:

the Government of Ontario is currently structured to provide services by ministries organized according to function. The need to coordinate functional services to meet the needs of various groups, including the mentally retarded, was one of the reasons for the reorganization of government into policy fields. An alternative organization into ministries serving client groups begs a more difficult task of coordination of function. Creation of a ministry for the handicapped would, in itself, be a form of institutionalization segregating handicapped residents from other citizens of Ontario. (19)

At federal and provincial levels of jurisdiction, government ministries have been dedicated to promoting the interests of designated populations, including Aboriginal peoples, children, women, veterans. Therefore, dedicating a ministry to the administration of policy for people with disabilities does not have to be problematic,

especially if it results in a more streamlined bureaucracy for people who currently access mental-health and disability supports.

At the beginning of the Dismantlement phase, the Ministry of Community and Social Services acknowledged that communities had “not yet provided sufficient resources to meet the service requirements of: people with both developmental and psychiatric handicaps who require services from both the health and social welfare systems; [and] medically fragile children and adults with multiple disabilities” (Government of Ontario, 1987, 21). Given the enduring confusion around distinguishing between mental illness and disability, coordinating policy just within the two ministries with primary responsibility for these populations- the Ministry of Health and Long-Term Care and the Ministry of Community and Social Services- could better serve the substantial population of people with dual diagnoses, and make more efficient use of finite resources. To that end, in 2006 the Ministry of Community and Social Services did propose addressing the issue of policy coordination in Ontario through

a strategy to promote cross-sector planning, service partnerships and learning by developing a protocol with the Ministry of Health and Long-Term Care. The strategy is intended to clarify expectations, roles, responsibilities and decision-making for transition planning. The purpose of the strategy is also to provide more consistency in how the policies are applied with regard to meeting the needs of people with a dual diagnosis (i.e. people with both a developmental disability and a mental health problem) and older individuals with a developmental disability who are moving to long-term care. (Government of Ontario, 2006, 25)

In 2008, the Ministry of Health and Long-Term Care (MOHLTC) and the Ministry of Community and Social Services (MCSS) did update an existing “Joint Policy Guideline



for the Provision of Community Mental Health and Developmental Services for Adults with a Dual Diagnosis”. However, as this is a “guideline” rather than an enforceable policy, a Vision where “[c]ommunity mental health and developmental services for persons with a dual diagnosis and their families will be integrated, coordinated and operate responsively and proactively both within and across sectors”(1) is essentially aspirational.

Still, there are recent examples of inter-ministerial collaboration to realize the objective of making communities more accessible for people with physical and mental disabilities. The Accessibility for Ontarians with Disabilities Act, 2005 (AODA) is administered by the Ministry of Citizenship and Immigration (I.2e). Under the auspices of this Ministry, services and agencies across ministerial jurisdictions seem to be coming together effectively to realize ambitious accessibility targets that must be met by all persons or organizations that “(a) provides goods, services or facilities; (b) employs persons in Ontario; (c) offers accommodation; (d) owns or occupies a building, structure or premises; or (e) is engaged in a prescribed business, activity or undertaking to meet such other requirements as may be prescribed” (Sec. 3). What sets the AODA apart from most disability policy is that it seems to consistently set the needs of people with disabilities as paramount over what is perceived to be feasible on the part of other stakeholders. In an era where social welfare provisions have been eroded<sup>73</sup> and the

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<sup>73</sup> A recent editorial in the *Toronto Star* suggests that current economic priorities undermines the Ontario government’s rhetorical commitment to community inclusion: “it is troubling to learn that in its 2010 budget, brought down in March, Ontario cut \$22 million that had been expected by some 380 organizations supporting people with developmental disabilities... The government knows the difficulties Community Living groups and other service providers face just keeping existing programs going, let alone expanding them to reduce the lengthy waiting lists. Indeed, while freezing the providers’ base budgets, the government found \$20 million to continue development of “transformation” plans. But it makes little sense to fund planning for a fairer and more sustainable system in the future while throwing the same organizations into a budgetary crisis today. If the government does not restore the \$22 million in funding,

commodification of services for people with mental disabilities has increased (Pedlar & Hutchison 642-645), policy that re-affirms the rights of all citizens to access and participate in their communities is vital to the realization of interesting and rewarding life outcomes.

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some organizations will be forced to cut off vital services and lay off staff. ...And the situation threatens to get worse, as a majority of those with developmental disabilities on the wait lists have parents over the age of 70. (Unkind Cut for the Disabled, para. 2-4, 6)

## **Conclusion**

Policy planners interpret life narratives to construct a rationale for policy. Then new stories demonstrate how policy plays itself out in individual lives. It is a cycle unto itself. Of course, dominant policy narratives cannot speak to each individual life story. Therefore, policy designed to support people with diverse abilities and needs must be flexible and offer a spectrum of services. Furthermore, social workers engaged in service delivery and planning need to realize that

[t]here are few presumptions in human relations more dangerous than the idea that one knows what another human being needs better than they do themselves. In politics, this presumption is a warrant to ignore democratic preferences and to trample on freedom. In other realms too, the arrogation of the right by doctors to define the needs of their patients, of social workers to administer the needs of their clients, and finally of parents to decide the needs of their children is in each case a warrant for abuse. (Ignatieff 11)

When people are perceived as being incompetent or unreliable self-advocates, they are at risk of being excluded from a shared social or cultural definition of humanity. Bringing these women and men back from the margins of society requires social workers to do more than recognize the right to equal access to the necessities of life. Social planning needs to acknowledge and validate what makes people different from each other, as well as what we have in common.

Reading stories helps social workers engaged with individuals, organizations or in planning to gain access to worlds we otherwise would not be able to experience. Several

researchers have found that people who read literature tend to have a greater capacity for empathy (Mar & Oatley 181). Social workers are trained to listen to life narratives and seek out opportunities to revise personal storylines, drawing from many disciplines and theoretical traditions. At the same time, disability is a social construction that is informed by a range of natural sciences, the social sciences and the humanities. Therefore, social workers should have some facility in undertaking an interdisciplinary approach to informing their practice from a range of theoretical discourses.

We turn to other people's stories, fiction and nonfiction, to help us make sense of our own (Tobin para. 1-4). Ian Brown and his wife, Johanna Schneller, slept alternate nights in order to provide round the clock care to their son. Yet Brown found his 'off' nights were more often spent reading than catching up on rest:

if he was asleep and I could stay awake, I could read, and did, voraciously. I have never appreciated words and books and time and the life of my mind more than I did on those stolen late nights. Dante, *The History of Mental Retardation*, books about deafness and about stuttering, novels about cowboys and reprobates, diaries of diplomats, Casanova's memoirs... Certainly I collected stories. I read Chesterfield's letters to his son, and Chesterton's dull detective novels, and anything that took me away: Elmore Leonard and Chandler and Roth and Updike, books about fathers and collecting and obsession, essays about any variety of inner life, lives of artists and millionaires, and of course every scientific paper about CFC. And newspapers. (Brown 49-50)

Reading from all kinds of sources and stories, Brown learned about different ways of being in the world. Perhaps all that reading helped him to be more certain about the

existence of Walker's own inner narrative, even if his son could not communicate it directly.

Critical reading teaches us that realizing more interesting and successful life outcomes for people with mental disabilities requires further community change. Jean Vanier believes that changing simplistic assumptions about the capacity of people with mental disabilities happens "[a]s we start to really get to know others, as we begin to listen to each other's stories, things begin to change. We no longer judge each other according to concepts of power and knowledge or according to group identity, but according to these personal, heart-to-heart encounters" (83). Vanier is alluding to a transactive planning process of mutual change, where social workers are not only contributing their expertise to solve a problem, they are open to revising their own relationship to the issue and their assumptions about the constituency with whom they are engaged. This can occur when social workers have the opportunity to form close working relationships with their clients.

Vanier speaks to the moral and ethical responsibility of knowing others, but there are also pragmatic reasons for working harder to obtain more complete stories about lives that are not easily accessible. Indeed, when it comes to working for people whose first-person narrative is difficult to access, a close relationship is a prerequisite to making an informed contribution to the planning process. The first step in constructing more meaningful life stories is to gather rich data. Social workers have a professional responsibility to create and maintain detailed case files to inform individual life planning, but also so that they may bring evidence-based data to program evaluations and policy planning. This should be obvious, but although there is often substantial bulk to client case histories, they tend to be very deficit-based and lack vital descriptive narrative that

depicts times and places where the individual has been happy in life. Reading widely allows social workers to “gather better data to strengthen planning capacity” (Government of Ontario, 2006, 12) and design more effective supports. Informing professional practice by reading from many different discourses, including novels, enhances our facility at recognizing inconsistencies and gaps in life stories and insight to try to fill them.

Being a critical reader also promotes reflexive professional practice that engages the social worker in an ongoing process of assessing how our personal values determine the possibilities that we can imagine for the people we serve. If no one can ever truly tell another’s story, social workers need to at least aspire to be reliable witnesses. Vanier says that “to witness is to tell our story” (90); and it is important for social workers and other advocates to recognize that the most informed perspective that we bring to a case note, a program design or a policy is based upon our understanding of other people’s needs. The translation may never be complete, but that does not absolve planners from the responsibility of considering as many sources as possible to inform a creative vision that is rich in potential, and backed by a commitment to advocacy to attain the supports required to realize it.

There is a tremendous amount of responsibility attached to speaking for the needs of people who are not able or empowered to speak for themselves. Michael Ignatieff concludes that “[o]ur needs are made of words: they come to us in speech, and they can die for lack of expression. Without a public language to help us find our own words, our needs will dry up in silence. It is words only, the common meanings they bear, which give me the right to speak in the name of the strangers at my door” (142). However, people who have the opportunity to form relationships with others who have little or no

language know that, in fact, needs are not *made* of words. Words are the most efficient tool that we have for communicating need, but needs are also expressed through a much more complex spectrum of human behaviour.

We need storytellers to continue to try to translate nonverbal experience into words. We need storytellers with the imagination to construct a narrative alternative that is more original than the tired either/or dichotomy of the sinister and oppressive asylum and the, for many people, unrealized objective of meaningful integration and security within the wider community. We need new storylines badly because the questions surrounding the interests of people with mental disabilities are not going to go away.

In fact, despite the ethical debates surrounding the potential ‘extinction’ of people with certain mental disabilities, as a result in advances in pre-natal testing and genetic sciences, the number of people with disabilities is only going to grow (Government of Ontario, 2006, 24). Many people today have disabilities that are more complex, and they will live longer lives than ever before; longer than their caregiver parents, which rarely used to happen.<sup>74</sup> Many more people will live long enough to acquire mental impairments in old age, and will require similar kinds of supports to navigate their lives as people who are born with disabilities. Indeed, the expansion of the long-term care system for seniors and the ethical debates about the quality of care that have accompanied it recall some of the debate that once surrounded the institutionalization of children with disabilities. The institutional debate is not over. It is just moving into a new phase. How

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<sup>74</sup> Referring to journal notes that he’s kept over the years since his son was born, Brown finds that the “*real problem is structural. Until recently, no one—certainly no part of the government-funding apparatus—was willing to admit that a child could be loved and still too difficult to be cared for by his or her parents. Because until twenty years ago, children this medically complex didn’t exist. They didn’t survive. High-tech medicine has created a new strain of human beings who require super human care. Society has yet to acknowledge this reality, especially at a practical level*” (96-97).

it continues to evolve will depend upon the stories we tell ourselves, and the policy that these narratives inspire.



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